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# Caregiver Religiosity, Spirituality, and Positive Emotion as Predictors of Psychological Well-being in Amyotrophic Lateral Sclerosis Patients

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Philadelphia College of Osteopathic Medicine

Department of Psychology

CAREGIVER RELIGIOSITY, SPIRITUALITY, AND POSITIVE EMOTION  
AS PREDICTORS OF PSYCHOLOGICAL WELL-BEING  
IN AMYOTROPHIC LATERAL SCLEROSIS PATIENTS

By Andrea Beth Weller

Submitted in Partial Fulfillment of the Requirements of the Degree of

Doctor of Psychology

November, 2009

**PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE  
DEPARTMENT OF PSYCHOLOGY**

**Dissertation Approval**

This is to certify that the thesis presented to us by Andrea Weller, on the 5<sup>th</sup> day of June, 2009, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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## Dedication

This thesis is personally dedicated to the memory of my grandmother, Opal L. Fetterhoff, who inspired me through her encouragement, love, and wisdom, and to her daughters, who tirelessly cared for her throughout the many years of her chronic illness. My grandmother's zest for life, reliance on spirituality, and positive attitude, against tremendous odds, will never be forgotten and will always be admired and exemplified in those she loved.

## Abstract

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disorder that results in degeneration of motor neurons of the cerebral cortex, the brainstem, and the spinal cord. Also known as Lou Gehrig's disease, ALS has no conclusive etiology and no known cure. The disease is ultimately fatal within approximately 3 to 5 years and robs individuals of all physical functions while leaving their intellectual capacity and personalities intact. Therefore, patients' quality of life (QOL) becomes increasingly important in their lives and in the lives of their caregivers. Patients with ALS and their caregivers face a number of psychological, psychosocial, and existential stressors. When caregivers demonstrate signs of depression and anxiety, functional impairment is likely transferred onto the ALS patient. Clearly, caregivers benefit from effective and adaptive coping strategies. Some researchers suggest that religiosity and spirituality may play a sustaining and buffering role when patients and caregivers face the stress of a terminal illness. Other researchers suggest that the cultivation of positive emotion can help psychological well-being over time. This was a cross-sectional study with data generated by ALS caregivers and patients using the following measures: Idler Index of Religiosity, Brief Multidimensional Measure of Religiousness/Spirituality, ALS Specific Quality of Life Questionnaire—Revised, Life Orientation Test—Revised, and Adult State Hope Scale. The following hypotheses were tested: (a) Patient negative emotion would be inversely correlated with patient religiosity and patient spirituality; (b) Caregiver hope would be directly related to patient religiosity and patient spirituality; (c) Caregiver optimism would be directly related to patient religiosity and patient spirituality; (d) Patient negative emotion would be predicted by caregiver hope, optimism, and religiosity

and spirituality over and above patient physical functioning, patient religiosity and spirituality, and level of care provided by the caregiver. Analyses of the data collected from the sample of ALS patients ( $n = 137$ ) and caregivers ( $n = 54$ ) did not support a strong relationship between caregiver distress and patient negative emotion and QOL. However, there was a small, and slightly obscure relationship, depending on the measure used, between patients' experience of negative emotion and practice of religiosity and spirituality. These results, although preliminary, support the notion that caregivers' psychological and physical states do not considerably impact, negatively or positively, patients' psychologically well-being. The present study did not find a relationship between patient negative emotion and the use of religiosity and spirituality as coping. For reasons perhaps inherent in the current sample of patients and caregivers, they did not utilize religious or spiritual experiences to cope with distress. Despite the results of the current study, we believe that caregiver well-being impacts patient QOL. Limitations of the study and clinical implications of coping with ALS are discussed.

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## CHAPTER 1

### Introduction

#### *Statement of Problem*

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is a rapidly progressing neurodegenerative disorder characterized by degeneration of motor neurons of the cerebral cortex, the brainstem, and the spinal cord (Rabkin, Wagner, & Del Bene, 2000). ALS is unremitting and progressive and often results in muscle weakness and a loss of function, followed shortly by respiratory failure (Bromberg, Anderson, Davidson, & Miller, 2001). The disease is ultimately fatal within approximately 3 to 5 years (Palmieri, 2005), with younger patients faring better than older patients (Sorenson, Stalker, Kurland, & Windebank, 2002). ALS progresses rapidly and steadily as it relentlessly takes away the afflicted individual's ability to walk and talk and to use gross motor skills, such as cutting meat and buttoning a shirt.

ALS eventually robs the individual of the ability to eat, swallow, and breathe. Weight loss and malnutrition progressively worsen, as do muscle atrophy, fatigue, and weakness (Palmieri, 2005). Individuals who develop ALS usually continue to have working intellectual capacity and functioning personalities (Neudert, Wasner, & Borasio, 2004). After a relentless course of losing most major and minor bodily functions, the patient with ALS will usually die from respiratory failure, aspiration, infection, or pulmonary embolism (Palmieri, 2005).

### *Quality of Life in Patients and Caregivers*

Quality of life (QOL) is an important factor in the lives of individuals with ALS and their caregivers. In this study, primary caregivers are operationally defined as spouses or domestic household partners who assumed primary responsibility for (a) the patient's emotional support, (b) the activities of daily living, (c) the administration of medications, (d) the provision of any special nutrition plan, and (e) other aspects of physical care during the course of the disease (Le, Leis, Pahwa, Wright, Ali, et al., 2003). In addition, reference to spousal caregivers is inclusive of primary caregivers married to patients with ALS, primary caregivers in common-law unions, and primary caregivers in same-sex partnerships.

There has been a growing interest in the QOL of ALS patients and caregivers. According to the World Health Organization (WHO), QOL is defined as the "individuals' perception of their position in life in the context of the culture and the value systems in which they live and in relation to their goals, expectations, standards, and concerns" (World Health Organization Group, 1998, p. 1570). QOL, as defined and described by the WHO, is multidimensional in nature and consists of six broad domains of QOL. The first domain, the physical domain, looks at the medical patient's level of discomfort, energy, pain, sensory functions, sexual activity, and sleep and rest (Skevington, 1998; WHOQOL Group, 1995). The second domain, the psychological domain, addresses body image, cognitions, negative and positive feelings, and self-esteem, (Skevington, 1998; WHOQOL Group, 1995). The third domain, level of independence, looks at the patient's

activities of daily living, communicative ability, dependence on medicinal substances, mobility, and occupational functioning (Skevington, 1998; WHOQOL Group, 1995). The fourth domain, social relationships, measures the medical patient's engagement in personal relationships, as well as social support activities (Skevington, 1998; WHOQOL Group, 1995). The fifth domain, the environment, looks at the patient's financial resources, home environment, safety and security, and work satisfaction (Skevington, 1998; WHOQOL Group, 1995). Finally, the sixth domain, which encompasses spirituality/religion/personal beliefs, describes the patient's general perception of health and QOL (Skevington, 1998; WHOQOL Group, 1995). This study focused on the psychological well-being and the social satisfaction components of QOL, as defined by the ALSSQOL—R subscales (e.g., negative emotion and satisfaction with people and the environment).

Although the disease process of ALS is comprised of repeated grieving for the loss of a familiar function, many patients find peace and worth in life. For decades, authors have reported the presence of optimism and positivism among patients diagnosed with the terminal illness of ALS (Viet, 1947). Low scores on depression scales in patients with ALS and their caregivers (see Rabkin, Wagner, & Del Bene, 2000) have caused researchers to look at other variables that may explain why a disabling illness, such as ALS, is not causing patients to become severely depressed, pessimistic, and despondent. According to Plahuta et al. (2002), a patient's lack of meaning in life and an external locus of control, not the patient's physical functioning, were major predictors of hopelessness. Moreover, Ganzini, Johnston, and Hoffman (1999) suggested a link between ALS patients' suffering and the construct of hopelessness.

When a patient's QOL is considered, treatment becomes more effective for the patient (Bremer, Simone, Walsh, Simmons, & Felgoise, 2004). Nelson, Trail, Van, Appel, and Lai (2003) conducted a study with 100 ALS patients to examine positive and negative QOL factors. Findings indicated that the majority of individuals reported that they coped using positive personality factors such as optimism, flexibility, and humor. The negative QOL group reported using 41% more spiritual strategies, including meditation and prayer, and endorsing 66% more stress responses than the positive QOL group (Nelson et al., 2003).

### *Positive Emotion*

The cultivation of positive emotion can help psychological well-being over time. Experiences of positive emotions prompt individuals to engage in adaptive activities instead of shying away from them (Fredrickson, 2001). Fredrickson and Joiner (2002) found that individuals who experienced more positive emotions became more resilient to adversity over time, as demonstrated by increased broad-minded coping. Furthermore, Fredrickson and Joiner suggested that enhanced coping skills predicted long-term positive emotions.

### *Religiosity and Spirituality*

Patients with ALS and their caregivers face a number of psychological, psychosocial, and existential stressors. As physical function lessens, patients and

caregivers experience significant changes in priorities and expectations about the illness (Bremer et al., 2004). Furthermore, as the disease progresses, different types of strain (e.g., financial, social, physical, time constraints) on the caretakers and patients likely cause the individuals to view their circumstances and coping resources differently (Clarke, Hickey, O'Boyle, & Hardiman, 2001). Some researchers suggest that religiosity and spirituality may play a sustaining and buffering role when patients and caregivers face the stress of a terminal illness (Bello-Haas, Hinders, Bocian, Mascha, Wheeler, et al., 2000; McClain, Rosenfield, & Breitbart, 2003; Nelson et al., 2003).

### *Caregiver and Patient Coping*

Given the devastating and predictable course of ALS, it is understandable that the progression of the disease will affect the entire family's psychological and spiritual QOL (McDonald, 2001). The impact of ALS on family caregivers is profound. For example, a report from the Cleveland Clinic Foundation found that primary caregivers spend an average of 11 hours each day caring for an ALS patient (Krivickas, Shockley, Saito, & Mitsumoto, 1995). It is typical for caregivers to face financial, psychological, and physical ramifications of caregiving. In fact, 50% of Krivickas and colleagues' participants' reported feeling physically and psychologically unhealthy, as well as financially distressed because of the increased expenses and reduced work hours.

When caregivers demonstrate signs of depression and anxiety, functional impairment is likely transferred onto the ALS patient (Goldstein, Adamson, Jeffrey, Down, Barby, et al., 1998). Moreover, stressed and unhealthy caregivers may experience

a loss of intimacy in their relationship with the patient (Goldstein et al., 1998) as well as myriad other psychological, social, and physical difficulties. Clearly, caregivers benefit from effective and adaptive coping strategies. According to Koenig, McCullough, and Larson (2001), religious or spiritual beliefs and behaviors provide caregivers with relief while caring for a sick loved one. Koenig et al. (2001) suggest that these behaviors are associated with greater meaning and purpose, a greater sense of well-being, and positive appraisals, and they foster adaptation to the caregiving role. Therapeutic directions have been adapted from literature in areas such as HIV/AIDS, cancer, and Alzheimer's disease to teach disease management, caretaking, and coping to patients and caretakers (Mitsumoto, Bromberg, Johnston, Tandan, Byock, et al., 2005).

### *Purpose of the Study*

The purpose of this study was to explore the extent of ALS patients' and caregivers' utilization of religiosity and spirituality as forms of coping during the disease process. Involvement in religious or spiritual activities may be important for the patient's and the caregiver's psychological, social, and physical well-being. Religion and spirituality can help to create meaning for the patient and for the caregiver at a time of confusion, incoherence, and devastation (see Bello-Haas et al., 2000). Both patients and caregivers find QOL issues important during the disease process. However, only recently have caregiver issues come to light in ALS research.

Examining the caregiver and patient relationship would help medical and mental health professionals to better formulate treatment options and provide a higher level of



holistic care to patients. It is important to understand the consequential nature of religion and spirituality as salient factors to QOL in both caregivers and patients with ALS. A better understanding of religiosity and spirituality would also provide professionals with more accurate information for educating ALS patients and caregivers on effective coping strategies.

### *Overview of the Theoretical Framework*

Cognitive-behavioral theory suggests that one's belief system will impact the interpretation of life events, such as illness in the self or in significant others, and lead to behaviors consistent with these beliefs (i.e., religious practices), which may influence one's feeling state (i.e., emotional well-being and satisfaction). Many religious individuals attempt to derive meaning from highly stressful events such as learning that a family member has a terminal illness. For example, cognitive-behavioral theory asserts that when religious individuals are diagnosed with terminal illness (activating event, A), they will attempt to utilize their religion or spirituality to make meaning from the experience (belief, B), which, in turn, influences the consequences or the outcome of the illness (consequences, C).

Positive psychology underlies the broaden-and build theory of psychology, which states that positive emotions broaden attention and cognition and enable flexibility and creative thinking, which, in turn, facilitate coping with stress and adversity (Aspinwall & Taylor, 1997; Fredrickson & Joiner, 2002). Positive emotions trigger an upward spiral of continued positive emotions and meaning within the individual. Finding meaning in

adversity also helps to increase positive feelings and emotions and, subsequently, to broaden positive thinking. As this cycle continues, researchers assert that individuals build psychological resilience and enhanced overall emotional well-being. Another outcome of broadened mind-sets is an increase in personal resources (Fredrickson & Joiner, 2002). Individuals who engage in an organized religion and/or spiritual activities may maintain higher QOL, psychological well-being, and satisfaction with others as ALS progresses, and they may have a more optimistic outlook on the disease process (Bello-Haas et al., 2000; Walsh, Bremer, Felgoise, & Simmons, 2003).

The theory of reasoned action notes that human behavior (behavioral intention) is influenced by one's attitude toward the behavior and the influence of the social environment and general subjective norms (i.e., person's perception of what others around him/her believe that the individual should do). Religion is a powerful influence in the lives of many individuals. It is important to realize that religion is not simply an intrapsychic phenomenon, but an ongoing social, reciprocal process for many individuals within their societies (Park, 2005). For instance, individuals acquire their systems of meaning from the larger society/culture in which they live and grow, particularly from their family and their subculture (Park, 2005). Individuals' larger cultural and religious institutions provide support to the families and reinforce the systems of meanings during stressful/crisis situations (Maton, Dodgen, Domingo, & Larson, 2005). In addition, religious meaning systems can have a powerful impact on societal well-being, functioning, and relationships with others (Pargament & Maton, 2000). Therefore, the religious or spiritual beliefs and practices of the caregivers may greatly impact the patient's belief system, the relationship with the patient, and the care that is given to the

patient. As a result, it is essential to understand the caregiver's coping resources (e.g., religiosity and spirituality and enhancement of positive emotions) and how they affect the patient's QOL and satisfaction with the relationship and the environment beyond the patient's own religiosity and spirituality.

### *Statement of Objectives*

1. To examine the influence of spousal caregiving variables, such as religiosity and spirituality, on the QOL of the ALS patient and caregiver
2. To examine the influence of spousal caregiving variables, such as positive thinking (e.g., optimism, hope), on the patient's engagement in religious and spiritual practices and patient QOL
3. To examine the cognitive belief system of the patient (e.g., ABC's of activating event, belief, and consequence), which affects the patient's engagement of religious practices
4. To contribute to the existing ALS literature by assessing how the caregiver and patient reciprocal relationship influences the patient's cognitive belief system, engagement in religious or spiritual activities, satisfaction with the environment, and how the social psychological interactions between the caregiver and the patient affects patient QOL.

## CHAPTER 2

### Review of the Literature

#### *Overview of ALS*

The purpose of this chapter is to provide a review of the background of ALS, the literature that presents religiosity and spirituality as a means of coping for caregivers of ALS patients, and an overview of the theories (e.g., cognitive-behavioral, social learning, and positive psychology) relevant to the present study. ALS has an extensive history and background, with characteristics that encompass social, psychological, and physical domains. The salient characteristics will be discussed in order to understand the depth and debilitation of the progressive disease. Maintaining good QOL, as defined by the World Health Organization, is essential to ALS patients and caregivers, as the terminal illness strips patients of the ability to function physically. Medical professionals focus on ways in which to increase patients' QOL because the disease takes a predictable and unremitting course toward physical decline and death. Patients and caregivers may turn to spiritual activities and religiosity to cope with the disease, the burden of numerous stressors, and the news that they or their loved one will die. However, not all patients diagnosed with ALS, and not all caregivers, use religious or spiritual means to cope with a diagnosis of ALS. Chronic illness takes a toll on spousal caregivers, marital relationships, and faith.

### *Diagnosis of ALS*

Diagnosing ALS is not usually a clear-cut task. In fact, it is challenging for most health professionals and extremely frustrating for most patients. Health professions most often rule out a myriad of other disorders before the diagnosis of ALS can be confirmed. Researchers and practitioners use the El Escorial criteria, developed by the Subcommittee on Motor Neuron Diseases (MND)/ALS of the World Federation of Neurology (WFN) at a meeting in El Escorial, Spain, in 1990 for the diagnosis of ALS (Belsh, 2000).

According to El Escorial criteria, the diagnosis of ALS requires the presence of (a) lower motor neuron degeneration, which is confirmed by a clinical, electrophysiological, or neuropathologic examination, (b) upper motor neuron degeneration, which is confirmed by a clinical examination, and (c) progressive spread of symptoms or signs within a region or to other regions of the brain, as determined by history or by a clinical examination (Brooks, 1994; Brooks, Miller, Swash, & Munsat, 2000). In addition, for a diagnosis to be made, the above criteria must be combined with the absence of (a) electrophysiological or pathological evidence of other disease processes that could explain the presenting symptomatology, and (b) neuroimaging evidence of other disease processes that might explain the observed clinical and electrophysiological signs. Finally, a careful patient history must be taken and supplementary tests (e.g., electrodiagnostic, neurophysiological, neuroimaging, and clinical laboratory studies) performed to exclude other disease processes from the labyrinth of ALS diagnostic criteria (Brooks et al., 2000).

### *Course of ALS*

ALS has varying onset and progression of symptoms. As the disease begins its dreadful course, most patients notice muscle weakness in one or two areas of the body, such as the arm or leg muscles or the bulbar muscles (e.g., speech and swallowing; Mitsumoto, 2001). Generally, one third of patients will notice weakness in the arm, one third will notice weakness in the leg, and one fourth of patients will develop weakness in the bulbar muscles (Mitsumoto, 2001). Other symptoms that may indicate ALS include clumsiness, muscle spasticity, fasciculations (muscle twitching), dysarthria (difficulty forming/speaking words because of muscle weakness), dysphagia (difficulty in swallowing), and fatigue (Palmieri, 2005).

There are many other common physical symptoms indicative of ALS, including muscle stiffness and difficulty walking, urinary frequency and urgency, swelling in the hands and the feet (Mitsumoto, 2001), and weight loss (Brooks & the ALS CARE Study Group, 2000). According to Mitsumoto (2001), muscle cramping is one of the most common initial symptoms, which occurs in approximately 80% to 90% of patients. It is often pain and muscle cramps that prompt individuals to consult a physician about the symptoms (Mitsumoto, 2001).

### *Classifications*

*Primary lateral sclerosis.* Primary lateral sclerosis is the first of three types of ALS onset. In this form, only the upper motor neurons degenerate while the lower motor

neurons remain undamaged; the limbs become stiff and spastic, but considerable weakness and atrophy do not occur (Mitsumoto, 2001). Common symptoms that patients may experience in this form of ALS include a loss of dexterity and muscle strength, spasticity, exaggerated muscle stretch reflexes (hyperreflexia), disinhibition of primitive reflexes (babinski sign), and spastic bulbar palsy (difficulty in speaking, chewing, and swallowing; Mitsumoto, 2001).

*Progressive muscular atrophy.* Progressive muscular atrophy is the second of three types of ALS onset. In this form, the lower motor neurons are affected. This leads to wasting and weakness in the muscles, combined with severe loss of reflexes (Mitsumoto, 2001). Some common symptoms seen with this progression of ALS are loss of muscle strength and atrophy, a loss of muscle stretch reflexes (hyporeflexia), a loss of normal muscle resistance (muscle hypotonicity/flaccidity), and muscle cramps (Mitsumoto, 2001).

*Progressive bulbar palsy.* Progressive bulbar palsy is the final type of ALS onset. This form encompasses a loss of all abilities to speak and swallow, and speech becomes slurred (Mitsumoto, 2001). Common symptoms include a weakened voice (dysarthria), impaired chewing and swallowing (dysphagia), drooling (sialorrhea), and aspiration (Mitsumoto, 2001).

### *Prevalence and Etiology*

Researchers have identified many types of ALS; however, two patterns are most prevalent among individuals. Sporadic ALS (SALS) occurs either in the presence of or in the absence of other preexisting diseases (Brooks et al., 2000; Mitsumoto, 2001).

According to Mitchell (2000), SALS encompasses 95% of reported cases. Health professionals have proposed many causes of SALS over the years; however, information remains inconclusive (Sinton, 2002). The other type of ALS is genetically determined. Better known as familial ALS (FALS), this type is present in one or more generations (Brooks et al., 2000) and affects approximately 5% to 10% of ALS patients (Sinton, 2002; Mitchell, 2000).

ALS is a universal disorder with a generally unknown etiology. Although there are differences in geography, climate, race, culture, and diet throughout the world, ALS occurs at approximately the same rate of one to two adults per 100,000 each year (Cwik, 2001) and is more prevalent in males than in females (Palmieri, 2005). Generally, ALS commences between the ages of 40 and 60 years (Palmieri, 2005). Researchers and health professionals have attempted to pinpoint etiological factors with little success.

Individuals with FALS may suffer from a gene defect or a mutation of the copper/zinc superoxide dismutase (SOD1) gene on chromosome 21 (Mitchell, 2000; Sinton, 2002). This does not explain the cause of the disease in SALS patients, nor does it explain the remaining causative factors for the patients who do not have the mutated gene (approximately 80% to 85% of FALS patients; Mitchell, 2000). Risk factors for SALS include a slow-acting virus; heavy metal poisoning; high exposure to solvents, pesticides,



and environmental toxins; previous trauma or severe injury; apoptosis (programmed cell death); and bacterial infection (Sinton, 2002). There is also speculation that electrical injury or exposure to strong electrical fields (Brooks & the ALS CARE Study Group, 2000), as well as environmental exposure to radiation (Mitchell, 2000), places an individual at risk for developing ALS.

Prevalence also differs depending on the type of ALS. According to Chiò (2000), the prevalence of ALS with an onset in the limbs is higher than the prevalence of ALS with an onset in the bulbar region. Progressive bulbar palsy is extremely rare, with most patients going on to develop classic ALS (Mitsumoto, 2001). Furthermore, Brooks and the ALS CARE Study Group (2000) found that 20% to 30% of ALS patients experienced twitching and cramping of the muscles, 30% experienced impaired use of an arm and a leg, and 2% to 18% of patients reported fatigue, weakness, thickness of speech, and problems swallowing and breathing.

### *Treatment*

There is no known treatment to stop the progression of ALS, but many available treatments help patients maintain QOL and independence as the disease progresses. Although ALS ravages the central nervous system and leaves the individual helpless and completely dependent upon caregivers, drug and nondrug therapies can help the patient manage pain and slow the progression of the disease. With no known cure, the medical treatment is largely palliative in nature with a focus on multidisciplinary support to help the patient maintain QOL for as long as possible (Palmieri, 2005).

*Drug therapies.* Recently, the FDA approved and released riluzole to aid in prolonging the life of patients with ALS. The drug acts by inhibiting the release of glutamate (an amino acid that in high amounts becomes toxic to individuals and causes cell death; Palmieri, 2005). According to Mitchell (2000), riluzole is safe and may increase median survival time by approximately 2 to 3 months in ALS patients. Vitamin E (tocopherol) may help to reverse the nutritional deficiency that, for many years, researchers believed may have resulted in ALS (Cwik, 2001). In addition, vitamin E appears to delay the onset or slow the progression of symptoms (Cwik, 2001). Additional drugs help to manage the secondary symptoms of ALS and may improve the patient's QOL (Gelinas, 2001; Palmieri, 2005).

*Nondrug therapies.* With the diagnosis of ALS come many changes, not only for the individual afflicted with the disease, but also for the family members. It is beneficial for the patient and the family to have a core team of individuals involved in treatment. The team plays an important educational and advocacy role for the family, as well as a supportive role (Jacobs & Mitsumoto, 2001). The core team members include the patient and the caregiver, neurologist, nurse coordinator, physical therapist, occupational therapist, speech pathologist, dietician, pastoral care coordinator, and social worker (Jacobs & Mitsumoto, 2001). These individuals each play a different role in the life of the ALS patient from diagnosing the disorder to discussing ongoing treatment options and maintaining the patient's QOL.

### *Cognitive Impairment*

ALS has generally been thought of as a discrete nosological disorder with degenerative pathology restricted to the pyramidal motor system (i.e., primary motor cortex and anterior horn of the spinal cord; Kilani, Micallef, Soubrouillard, Rey-Lardiller, Demattei, et al., 2004). However, ALS can also be associated with signs of cortical and extrapyramidal degeneration in other areas of the brain, including the cortex, hippocampus, basal ganglia, and frontal lobe (Ince, Lowe, & Shaw, 1998; Kilani et al., 2004). In fact, the cognitive impairment displayed by some ALS patients has resembled symptoms of dementia (e.g., impairment in verbal fluency, difficulties finding words, attention deficits, and neuropsychological deficits typical of frontal lobe dysfunction in ALS patients without clinical signs of dementia; Abrahams, Leigh, Harvey, Vythelingum, Grise, et al., 2000). The overlap in the symptomatic presentation between the cognitive impairment during the course of ALS and other disorders (e.g., dementia or Alzheimer's disease) creates difficulty for practitioners and researchers in distinguishing between different diseases (Kilani et al., 2004). Thus, the first signs of cognitive impairment in ALS patients may easily be misdiagnosed as a mood disorder such as depression or emotional dyscontrol (e.g., frequent laughing and crying or inappropriate emotional expression), which implicates the frontal subcortical circuits of the brain (Kilani et al., 2004). Furthermore, astrocytes, the largest population of cells in the central nervous system, interact closely with neurons (Julien, 2007). In response to injury, astrocytes become activated and grow displaying morphological changes in gene expression that may be toxic or pathological to the individual (Julien, 2007). Current research shows that

astrocytes may be important in motor neuron degeneration and contribute to, rather than initiate, disease progression (Julien, 2007; Yamanaka, Chun, Boilee, Fujimori-Tonou, et al., 2008).

Many of the cognitive deficits in ALS patients have been detected using a number of neuropsychological test batteries, including the Wisconsin Card Sort Test (WCST), Picture Arrangement, and the Tower of Hanoi (Kilani et al., 2004). Additionally, researchers use psychophysiological tests to detect cognitive dysfunction, including the single photon emission computerized tomography (SPECT) or positron emission tomography (PET) studies showing hypoactivity, as measured by decreased glucose utilization or cerebral blood flow in the frontal cortex (Abe, Fujimura, Toyooka, Sakoda, Yorifuji, et al., 1997), prefrontal areas (Lloyd, Richardson, Brooks, Al-Chalabi, & Leigh, 2000), limbic system (Kew, Goldstein, Leigh, Abrahams, Cosgrave, et al., 1993), and thalamus (Abrahams, Leigh, Kew, Goldstein, Lloyd, & Brooks, 1995; Kew et al., 1993). Essentially, this pattern of degeneration indicates that ALS may ultimately involve a multisystem degeneration.

### *Psychological Considerations*

#### *Adjustment to ALS*

The symptomatic profile of ALS, coupled with the progressiveness of the disease, takes a toll on the mental health of both the patient and the caregiver. As the illness strips the patient of former functions, a grieving process occurs for both the patient and the

patient's support system. With the diagnosis of ALS comes a myriad of psychological changes that may persist through the duration of the illness. For example, it is common for a diagnosis of ALS to affect a patient's work, financial, and personal relationship status (Jacobs & Mitsumoto, 2001). Furthermore, patients with ALS may experience emotional and social adjustment to the terminal diagnosis, and as the patient's physical function declines, the roles within the family may change and become a different type of challenge to each member (Jacobs & Mitsumoto, 2001). Although the patient and the caregiver struggle to adjust and respond to the enormous changes and demands of the threat imposed by the disease (Weitzner, McMillan, & Jacobsen, 1999), it is possible to lead a high quality life, regardless of the functional restraints imposed by ALS (McDonald, 2001).

### *Quality of Life*

It is important for patients and caregivers to realize that despite the presence of severe physical disability, many patients with ALS are able to live rich and active lives. Young and McNicoll (1998) identified five important coping factors: (a) cognitive appraisal, (b) reframing, (c) intellectual stimulation, (d) wisdom, and (e) interpersonal relationships. McDonald (2001) added the coping strategies of maintaining a sense of hope, sharing in the lives of significant others, and seeking help from others. The presence of a positive attitude, positive thought patterns, and positive coping skills may also lead to higher QOL in ALS patients.

Quality of life encompasses the individual's physical symptoms of the illness, the psychological and emotional responses to the illness, and the social and interpersonal aspects of the illness (Bremer et al., 2004). Quality of life in ALS patients is essential to study because of the terminal nature of the disease. For example, realistically, patients with ALS have an average of 3 to 5 years' survival time after the initial diagnosis (Haverkamp, Appel, & Appel, 1995; Traynor & Hardiman, 1998); therefore, the patient's QOL issues overshadow problems in his/her strength and physical functioning (Simmons, Bremer, Robbins, Walsh, & Fischer, 2000). Realistically, death is inevitable for ALS patients; therefore, the focus should be on QOL.

Given that ALS is an incurable illness, the primary goal for patients and professionals is to focus on QOL and ways in which to optimize the patient's and the caregiver's psychological, social, and physical functioning (Simmons, 2005). As a result, it is essential that a core team of professionals surround the patient and the family to help with each transition as it occurs (Jacobs & Mitsumoto, 2001; Simmons, 2005). Morrie Schwartz, an ALS patient, focused on the meaning of life, and he taught that meaning to others: "Once you learn how to die, you learn how to live" (Albom, 1997, p. 82). Moreover, after Morrie received a diagnosis of ALS, he wanted life to progress as usual with his family and friends, "Do not stop your lives," he said. "Otherwise, this disease will have ruined three of us instead of one" (Albom, 1997, p. 93). Similarly, author and ALS patient William Sinton reported, "As I began to lose my abilities, I realized that I should not dwell on what I had lost, but rather, I tried to look at what I could do" (2002, p. 13). Moreover, Nordeson, Engström, and Norberg (1998) found more than half of their sample of patients with progressive neurological disorders ( $N = 52$ ) continued to view

their bodily functioning as good, despite their terminal illness. Fifty-one percent of Nordeson and colleagues' sample rated life as rather good, while another 36% rated it as good or very good. Green et al. (2003) found similar results in their sample of 77 ALS patients. For example, patients valued their health-related QOL, even when their physical health status was reportedly very poor. Essentially, despite the consistent loss of familiar functions, chronically ill patients experience new learning processes and many patients find ways to continue enjoying life (Gascho & Derrickson, 2006).

### *Progression of Psychological Symptoms*

Studies have documented the range of emotions experienced by ALS patients and caregivers as the disease taxes patients' QOL. A diagnosis of ALS brings with it a wide range of stressors for patients and caregivers. Individuals with ALS and caregivers often experience feelings of isolation, loss of traditional roles (e.g., work, family, spouse, friend, lover, parent), financial worry, embarrassment, and a loss of leisure time (McDonald, 2001). Patients and caregivers may experience depression, anxiety, and various physical disturbances throughout the course of the disease that pose adjustment difficulties for both the patient and the family members (Jacobs & Mitsumoto, 2001). Family caregivers are at increased risk for experiencing symptoms of depression, anxiety, role restrictions, strained marital relations, and diminished physical health (Sales, Schultz, & Biegel, 1992), as well as unmet personal, psychological, social, financial, and spiritual needs (Sales et al., 1992). As ALS progresses, patients sense the caregiving

stress and tend to worry that they are burdening their family members (Ganzini, Johnston, & Silveira, 2002).

When facing the loss of a loved one, caregivers may experience normal anticipatory grief while engrossed in the process of caring for the terminally ill patient. Although caregivers of terminally ill patients likely become more emotionally and physically taxed than patients, they may not be more depressed and distressed than patients. In a recent study conducted by Adelman, Albert, Rabkin, Del Bene, Tider, and O'Sullivan (2004), researchers compared ALS patients and caregivers on their physical and psychosocial perceptions of burden. Adelman and colleagues found high agreement between patients and caregivers on patient pain, control over ALS, optimism, and the will to live. Less agreement emerged on patient suffering and caregiving burden. Patients in the sample assumed that their care was more burdensome than it was to the caregiver, while caregivers assumed patients suffered more than they admitted. Finding meaning in the caregiving experience tends to help caregivers adapt and cope more easily with the disease process and with the overall caregiving experience. For example, Rabkin et al. (2000) found that caregivers exhibited less depression when they were able to find meaning in the caregiving experience.

### *Caregiver's Experience*

Caregivers experience many losses, responses, feelings, and stages that encompass the downward trajectory of a loved one's terminal illness, starting at the onset of the illness and lasting beyond the death. Caregivers often experience anticipatory grief,



or what has been termed *caregiver grief*, while caring for a chronically ill individual (Sanders & Saltz, 2003). Caregiver grief is described as the intellectual, affective, and existential elements of adapting to the caring demands and expectations (Meuser & Marwit, 2001). In fact, in an exploratory descriptive study conducted at a hospice on patients and caregivers, Waldrop (2007) found that caregiver grief during end-stage care encompassed heightened levels of anxiety, depression, restlessness, fear, tenseness, trouble remembering and concentrating, and difficulty completing tasks. Furthermore, caregivers reported intense emotions of sadness and anger, as well as social isolation and intense moodiness, which paralleled the patient's decline in functioning. Caregiver functioning does not improve rapidly after the loved one's death. According to Waldrop, anxiety and hostility decreased significantly in the caregiver sample; however, loneliness, sadness, and tearfulness increased, as did trouble concentrating, remembering, and completing tasks. Caregiver grief appears to be highly influenced by social support, including the presence of (cohesive or conflicted) family, friends, and connections with church groups.

Many studies in other health-related disciplines, such as oncology, neurology (e.g., Alzheimer's disease, dementia, Parkinson's disease), severe mental illness (e.g., schizophrenia) and even HIV and AIDS have addressed caregiver coping more extensively than research in the area of ALS. Of the studies conducted on ALS, some focused on the resilience of caregivers (Rabkin et al., 2000), the burden of caregiving (Hecht, Graesel, Tigges, Hillemacher, Winterholler, et al., 2003), the stressors of patients and caregivers (Trail, Nelson, Van, Appel, & Lai, 2004), and the clinical or demographic factors associated with QOL in patients and caregivers (Lo Coco, Lo Coco, Cicero,

Oliveri, Lo Verso, et al., 2005), yet few focused on the existential and general coping factors of caregivers. Although the relationship, emotions, and coping response of patients and caregivers who face ALS appear similar to other health-related patients and caregivers, many times, marked differences exist with regards to demands and issues, individual perceptions, public awareness, and the amount of available outside support.

### *Oncology Caregivers*

Caregivers of chronically ill patients tend to meet the needs of the ill patient at their own expense. When caregivers are not meeting their own needs successfully, it causes poor health for caregivers and a possibility that patients' necessities will not be met. In a longitudinal study conducted by Soothill, Morris, Harman, Francis, Thomas, and McIlmurray (2001) with 32 caregivers of cancer patients, 43% of the sample reported significant unmet needs ranging from managing daily functions (e.g., fatigue, finances, diet, housework, transportation) and emotions (e.g., guilt, anger, sadness, fears, and uncertainty) to difficulty in relationships (e.g., sexual needs, social activities, appearance, loneliness, alone time, and maintaining independence). This study underscores the range of unmet needs for caregivers of terminally ill patients and the need for caregivers to become involved in social support networks to ensure that they continue to meet important relational and social needs. In a similar study on oncology caregivers, Redinbaugh, Baum, Tarbell, and Arnold (2003) found a significant relationship between caregiving stress and caregiver outcomes. For example, greater caregiver strain was directly related to greater patient needs in activities of daily living

(ADL), psychological distress, and poorer patient existential QOL. On the other hand, reframing the event, defining the illness in a manageable way, and engaging in improved problem-solving strategies led to lessened caregiver strain. Furthermore, caregivers of terminally ill patients with cancer identified three main stressors as patient needs in ADL, patient symptoms, and patient decline in QOL (Axelsson & Sjoden, 1998). Yet when caregivers of cancer patients denied the likelihood of a loved one's terminal prognosis, they coped more effectively with the caregiver burden (Redinbaugh et al., 2003).

### *Alzheimer's Disease Caregivers*

Theoretically, the stress and coping model developed by Lazarus and Folkman (1984) is most abundantly used to address caregiver coping for Alzheimer's disease patients. With regards to Alzheimer's disease caregivers, Coen, O'Boyle, Swanwick, and Coakley (1999) reported an association between the intensity of caregiving stress and psychological distress and burden. Caregivers of Alzheimer's disease patients used increased social support, confidence, and mastery, as well as active problem-solving strategies, to promote better psychological adjustment and to decrease stress levels (Schulz, O'Brien, Bookwala, & Fleissner, 1995).

### *HIV/AIDS Caregivers*

Literature in this area supports the use of spirituality in helping caregivers cope in a positive manner during terminal illness. In a study conducted by Folkman (1997) with

caregivers and partners of persons dying of AIDS, religious and spiritual beliefs and activities were averaged over a 2-year period. At baseline, for both bereaved and nonbereaved caregivers, spiritual beliefs and activities significantly correlated to positive affect, purposeful problem solving, and positive reappraisal. Folkman concluded that spiritual beliefs provide supportive coping in the days surrounding the death of a partner.

### *ALS Caregivers*

Caregivers of ALS patients face a myriad of stressors. In a comparative study conducted by Trail et al. (2004) on ALS caregivers' and patients' stressors, researchers found that caregivers identified their top three stressors as illness progression, swallowing and eating abilities, and patients' emotional and physical well-being. The authors reported the patients' top three stressors as illness progression and dependency issues, problems talking, and muscle weakness. Trail and colleagues attributed the differences in the study between patients and caregivers to expectations about the illness and its progression.

To provide the best care for patients, ALS caregivers should remain aware of their cognitive state and feelings. Many caregivers find that providing loved ones with steady care taxes their social, economic, and psychological reserves. Recent research has expounded upon what factors remain most important to patients and caregivers as ALS progresses and the patient's health declines. Trail et al. (2004) reported no statistically significant differences among the physical, psychosocial, and existential domains in 66 ALS patients and 61 caregivers. However, more patients and caregivers expressed

existential concerns (e.g., worries about future, loss of faith) than physical concerns (e.g., muscle weakness, mobility) and psychosocial concerns (e.g., financial, stress, depression). Existential concerns were reported by 86.4% of patients and 79.7% of caregivers, whereas 80.3% of patients and 76.3% of caregivers expressed physical concerns and only 41% of both groups cited psychosocial concerns.

According to a study conducted by Ganzini and colleagues (1999) with 100 ALS patients and 91 family caregivers, the caregivers reported struggling substantially, as 24% reported that the patient did not have adequate finances to cover expenditures for medical care and equipment, 37% had lost income because of caregiving, 18% had to quit work to care for the patient, and 12% had become ill while caring for the ALS patient. Ganzini and colleagues also found that when caregivers did not take time for themselves while caring for their loved one, 23% reported diminished social lives, 22% reported no time for themselves, 33% felt stressed by the caregiving experience, and 24% reported feelings of depression.

Caregiver coping with ALS may be a cyclical pattern that repeats itself many times each day. According to Cobb, Reckling, and Fernegel (2001), many caregivers fit into five general categories as they attempt to cope with the daily experience of ALS in the life of a loved one. The first category, according to Cobb and colleagues, is *taking it*. Taking it refers to an awareness of the caregiver's thoughts, feelings, and perceptions of a seemingly uncontrollable event that suddenly entered their lives and, subsequently, making a commitment to the unknown situation. The second category, *staying afloat/holding it together*, describes an attempt to maintain normalcy in the face of an impending crisis and continuous tensions and stressors. The third category, *losing*

*ground*, describes the caregiver's continual experience of loss. The fourth category, *regrouping*, relates to regaining control either by seeking further information, strengthening religious and/or spiritual bonds, or gaining emotional assistance from within the self or from others. Finally, *holding it together* occurs again, which is simply maintaining and "making the most of the situation," attempting to understand, accept, and continue to adjust (Cobb et al., 2001, p. 251). Olex (2006) described a similar phenomenon of grief and coping themes in a sample of 15 caregivers as they faced daily battles with grief in an attempt to move forward. Moreover, Olex found that many ALS caregivers learned from other caregivers and needed help moving forward, reframing the event, and planning for the future.

### *Clinical Implications for Patients and Caregivers*

There are many ways for caregivers to increase their psychological health, including increasing the availability of a social support network (Weitzner et al., 1999), opening their access to communication with the ALS patient, increasing genuine relaxation (e.g., telling jokes/stories together, singing favorite songs, watching a movie; McDonald, 2001), and reframing the illness as "just an event" to put the diagnosis into perspective for the patient and the caregiver, as well as to acknowledge the sense of why the illness has occurred to the patient and to the family (O'Connor, Wicker, & Germino, 1990). To improve caregivers' emotional well-being, it may be helpful to not only target caregivers' support systems and functional capacities directly, but also to improve the

caregivers' psychological functioning by indirectly expanding the patients' QOL domains.

Considering the reciprocal relationship that many caregivers and patients share, as well as the amount of time spent together, positive coping strategies should be in place as early as possible for both patient and caregiver. According to a study conducted by Northouse and colleagues (2002) with 189 recurrent breast cancer patient/family dyads, the researchers found that self-efficacy, social support, and family hardiness had a positive effect on the caregivers' QOL, which positively impacted the caregiving experience. On the other hand, the patients in the study who experienced distress, concerns, hopelessness, and negative cognitive appraisal transferred negative emotional affects onto the caregivers' mental health and overall functioning.

Physicians should acknowledge the importance of patients' spirituality and religious beliefs to their treatment. All medical professionals should record a spiritual history as a routine part of the intake while interviewing new patients (D'Souza & George, 2006). Additionally, the effectiveness of cognitive therapy increases when it is integrated with the patients' spiritual and belief system (D'Souza, Rich, Diamond, Godfrey, Gleeson, 2002). Furthermore, when physicians integrate patients' spiritual and religious beliefs into treatment, patients tend to exhibit greater overall satisfaction with the physician-patient relationship, greater medical compliance with the treatment, and greater comfort with the physician recommendations and suggestions (D'Souza, 2002; D'Souza & George, 2006).

### *Theoretical Framework of the Current Study*

#### *Cognitive-Behavioral Theory of Religiosity/Spirituality*

Religion is a primary avenue used by individuals to make sense of the world. Religion helps provide meaning to daily functions as well as to more specific problematic, incoherent, and confusing situations or circumstances (Ozorak, 2005; Park, 2006). Many religious individuals attempt to derive meaning from highly stressful events, such learning of a diagnosis of a terminal illness in themselves or a family member. For example, the cognitive-behavioral theory asserts that when religious individuals are diagnosed with terminal illness (activating event, A), they will attempt to utilize their religion or spirituality to make meaning from the experience (belief, B), which, in turn, influences the consequences or the outcome of the illness (consequence, C).

Religion, as a core schema, informs beliefs about the self, the world, and interaction with others (McIntosh, 1993), and it helps individuals understand mundane and unexpected occurrences (Spilka, Hood, Hunsberger, & Gorsuch, 2003). Religion may change the appraised meaning of stressful situations by helping individuals see the positive aspects in the situation (Park, 2005). For example, Park (2006) demonstrated a link between positive appraisal of stress and subsequent adjustment in a sample of 83 older religious adults. Religion tends to offer individuals an avenue for making a positive reattribution or for reframing the situation during stressful times by relying on a higher power. For example, individuals often come to see the stressful event as the will of God (Park, 2005), a higher power who would not give them more than they could handle. In



contrast, some individuals may see a stressful event, such as an illness or death, as a spiritual opportunity or as the result of human sinfulness or punishment by God (Pargament, 1997). Nonetheless, whether a positive or a negative belief derives from the activating event, research suggests similar consequences (Frazier, Tashiro, Berman, Steger, & Long, 2004). Similarly, Park (2005) found that bereavement was associated with more initial distress in religious individuals, as seen by higher levels of intrusive thoughts, avoidance, and depressed mood. However, as time progressed, the effects disappeared in religious individuals, and researchers observed more positive associations between religion and long-term adjustment.

#### *Social Learning Theory and Theory of Reasoned Action*

Religion is a powerful influence in the lives of many individuals. It is important to realize that religion is not simply an intrapsychic phenomenon, but an ongoing social, reciprocal process for many individuals within their societies (Park, 2005). For instance, individuals acquire their systems of meaning from the larger society or culture in which they live and grow, particularly from their family and their subculture (Park, 2005). These religious meaning systems can have a powerful impact on societal well-being, functioning, and relationships with others (Pargament & Maton, 2000). Moreover, larger cultural and religious institutions provide support to families and reinforce the systems of meanings during crisis situations (Maton et al., 2005). Therefore, the religious or spiritual beliefs and practices of the caregiver may greatly impact the patient's belief systems, the relationship with the patient, and the care that is given to the patient.

### *Broaden-and-Build Theory of Positive Psychology*

Positive psychology underlies the broaden-and-build theory of psychology, which states that positive emotions broaden attention and cognition and enable flexibility and creative thinking which, in turn, facilitate coping with stress and adversity (Aspinwall & Taylor, 1997; Fredrickson & Joiner, 2002). Positive emotions trigger an upward spiral of continued positive emotions and meaning within the individual. Finding meaning in adversity also helps to increase positive feelings and emotions and, subsequently, to broaden positive thinking. As this cycle continues, researchers assert that individuals build psychological resilience and enhance overall emotional well-being. Another outcome of a broadened mind-set is an increase in personal resources (Fredrickson & Joiner, 2002).

The field of positive psychology generally encompasses subjective experiences including well-being, contentment, satisfaction, hope and optimism, happiness, and self-determination (Seligman & Csikszentmihalyi, 2000) that may lead to more successful coping with health challenges and better overall physical health (Segerstrom, Taylor, Kemeny, & Fahey, 1998). According to Seligman and Csikszentmihalyi (2000), the field of psychology is not simply about “pathology, weakness, and damage,” it is also about “strength and virtue” (p. 7). Rather than focusing on the deficits within an individual, positive psychology focuses on the positive traits that lead to growth, with a mission to strengthen them (Berman & Davis-Berman, 2005). Once they are strengthened, the traits of positive emotions, positive individual traits, and prosocial attitudes (Seligman &

Csikszentmihalyi, 2000) lead to the development of a stable personality and increased resiliency (Fredrickson, 2001), optimism (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000), and overall better physical health (Salovey, Rothman, Detweiler, & Steward, 2000). Patients who utilize positive psychology and preventive measures in their daily self-care plan will be more resilient to challenges, more optimistic in their daily activities, and better able to handle stressful situations flexibly, effectively, and open-mindedly.

*Patient-caregiver connection.* The patient and caregiver spend a significant portion of time together during a terminal illness. The distress inherent to the role of caregiving is well known in the literature (Adelman et al., 2004; Mitsumoto, 2002; Rabkin et al., 2000; Taylor, 2006; Theis, Biordi, Coeling, Nalepka, & Miller, 2003). For example, distressed caregivers tend to experience increased rates of depression, financial burden, hopelessness, fatigue, and anxiety (Rabkin et al., 2000). However, Rabkin and colleagues found that when caregivers reframed the experience from seeing it as a burden to something meaningful, the caregivers adapted more readily and coped more effectively. The concept of reframing is important because Rabkin and collaborators identified a high concordance rate (+ .55 to + .72) of distress between samples of 56 patients and 31 caregivers on measures of depression, anxiety, and QOL. The implications suggest that observations of caregiver distress by patients may add to the perception of being a burden which, in turn, may exacerbate patient distress. The Rabkin study provides evidence that caregivers need to monitor their mental health closely to ensure that their distress does not filter to patients. Furthermore, recent research suggests that marital relationship satisfaction is moderated by the level of social support, rather

than severity of impairment, in individuals with neurological illnesses (O'Connor, McCabe, & Firth, 2008). O'Connor and colleagues found significantly higher perceived levels of social support among patients ( $n = 423$ ) than caregivers ( $n = 335$ ), indicating that support services often focus on patient needs, which leaves caregiver needs unmet. In a relationship where patients are capable of “taking” yet incapable of “giving,” caregivers of terminally ill individuals must find other sources of social support so that negative thoughts and feelings are not transferred onto the patient inadvertently (O'Connor et al., 2008). Religion or spiritual activities provide an outlet for creating positive meaning systems, support systems, and coping resources (e.g., prayer, fellowship) that increase caregiving meaning and resiliency, relationship satisfaction, and overall support and care for the patient.

### *Theoretical Constructs*

*Religiosity.* Generally, religiosity refers to an affiliation with an organized or institutionalized religion (Daaleman & Vandecreek, 2000). According to Koenig et al. (2001), religion involves (a) a search for nonsacred goals, either inside or outside a religious setting, which may involve attending religious services in order to increase social contacts, to improve one's status in the community, or to attain some other benefit not associated with the divine; and (b) a set of behaviors validated and supported by a definable group of people, which are conducted in search for the sacred. Overall, religion appears to be an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred and to others (Koenig et al., 2001, Reyes-Ortiz, 2006).

*Spirituality.* In contrast to the understanding of religion, spirituality does not depend upon an institutional context (Pargament, 1997) and characterizes a search for what is sacred, internalized, and individualized (Daaleman & Vandecreek, 2000). Spirituality appears to be the private pursuit for meaning and answers to questions about life and relationships, which may or may not lead to the development of religious rituals and the formation of a sense of community with others (Koenig et al., 2001). Spirituality refers to a transcendent relationship between the person and the higher being/power, a quality that some individuals believe goes beyond a specific religious affiliation with, and attendance at, an organized church or institution (D'Souza & George, 2006).

*Quality of life.* According to the WHO, QOL is a multidimensional construct consisting of six broad domains (explained in chapter 1). This study focused on three of those domains: psychological, social relationships, and spirituality/religion/personal beliefs (Skevington, 1998; WHOQOL Group, 1995). QOL is most often determined by non-health-related factors, such as family, friends, and work (Simmons et al., 2006). In the current study, the QOL construct is primarily represented by the ALS patient's amount of negative emotion and social satisfaction, as measured by the Amyotrophic Lateral Sclerosis Specific Quality of Life Questionnaire—Revised (ALSSQOL—R), and the patient's involvement in spiritual/religious endeavors, as measured by instruments described elsewhere.

*Optimism.* Optimism is generally defined as a unique set of coping skills that helps individuals persevere through difficult situations (Scheier, Carver, & Bridges, 1994). Optimism is a pervasive view, a schema or a lens, through which individuals see the world. It not only affects how people look at the world and interpret circumstances, it also affects their behavior and the way in which individuals manage and enact their thoughts and feelings and likely their effort toward a situation. Optimistic persons possess the ability to adjust more quickly and favorably to life transitions (Aspinwall & Taylor, 1992), hold positive expectations for the future (Scheier et al., 1994), and utilize enhanced coping resources, including spontaneously responding to hypothetical situations (Scheier, Weintraub, & Carver, 1986) and improved coping with serious diseases (Friedman, Nelson, Baer, Lane, Smith, et al., 1992). Individuals who exhibit optimistic traits also tend to utilize problem-focused coping strategies (Scheier et al., 1994) that include disease management (e.g., information-seeking and support-seeking) strategies rather than emotion-focused coping, which focuses on releasing emotions connected to the disease process. Scheier and colleagues found a connection between the constructs of optimism and self-esteem in the context of self-worth. Additionally, Scheier and colleagues found that optimistic individuals were high in self-mastery (the perception of control over events in one's life; Pearlin & Schooler, 1978) and low in neuroticism (self-doubt, emotional lability, and worry).

Optimists hold positive expectations for the future, feel less distress over situations, and exhibit better psychological adjustment to a range of stressors (Nes & Segerstrom, 2006). The presence of optimism improves physical and psychological health and creates valuable psychological resources. When individuals gain control and

find meaning in life, they are able to cope more effectively with challenging events (Taylor et al., 2000). Stressful events do not always lead to a negative outcome; they can be learning experiences that result in growth such as improving coping skills, enhancing social relationships, and prioritizing responsibilities (Taylor et al., 2000). According to Taylor and colleagues (2000), the way to achieve optimism is by gaining a sense of personal control and by discovering meaning in life's experiences. These psychosocial resources are akin to "reserves" during stress (Taylor et al., 2000). Essentially, the ability to cope, that is, "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984 p. 141) is a primary reason that optimistic individuals adjust to negative circumstances more quickly than their nonoptimistic counterparts.

*Hope.* Hope is operationally defined as a perception that one is able to achieve desired goals (Erickson, Post, & Paige, 1975). This manner of goal-directed thinking plays an important role in the attainment of positive outcomes (Snyder, Sympton, Ybasco, Borders, Babyak, et al., 1996). According to Snyder and colleagues (1996), the presence of *state* hope is related to goal-directed thinking, ongoing self-esteem, positive affect, and positive daily appraisals. Additionally, hope is a cognitive set comprised of two goal-related constructs: agency and pathways. Pathways thinking refers to thoughts that an individual can generate for attaining goals, and agentic thinking refers to the perceptions involving an individual's capacity to initiate and sustain movement along the chosen pathways (Irving, Snyder, & Crowson, 1998). Both conceptualizations of hope have their roots in goal-directed and problem-solving theories and tend to increase an

individual's ability to cope with detrimental circumstances by employing a more problem-focused and goal-directed schema to deal with the situation. Consider an example of two individuals who recently learned of their ALS. The first individual does not believe in mobilizing strategies (e.g., seeking treatment and information) or implementing proactive techniques that may slow the deterioration of the disease process (i.e., no pathways, therefore no agency). The second individual believes that early detection and treatment can provide a sense of control, allowing them to better handle the disease process with the help of doctors, family members, and church friends (high pathways thinking). Additionally, the second individual's motivation (agency) provides goal-directed thought and effective coping (Irving et al., 1998).

Hope gives life meaning, direction, and an optimistic focus, and hope can provide individuals with an ability to see the current situation as transitory and fleeting (Borneman, Stahl, Ferrell, & Smith, 2002). Hope also provides confidence, inspiration, energy, and focus during obstacles and challenges. According to Irving et al. (1998), terminally ill individuals who exhibit a hopeful schema (a) possess knowledge about the problem, (b) exhibit a challenging rather than a threatening appraisal/schema of the situation, and (c) identify strategies for coping with the adverse events (Irving et al., 1998). Furthermore, Herth (1990, 1993) proposed that hopefulness or hopelessness of the patient or family member affects the other through a reciprocal (interdependent) relationship as coping mechanisms are enhanced or depleted. The author identified six hope-fostering strategies (sustaining relationships, cognitive reframing, time refocusing, attainable expectations, spiritual beliefs, and uplifting energy) and three hope-hindering strategies (isolation, concurrent losses, and poorly controlled symptom management)



with 25 family caregivers and terminally ill patients who had cancer, ALS, AIDS, pulmonary disease, or cardiac disease (Herth, 1993). Similarly, Borneman and colleagues noted that 51 family caregivers maintained a high level of hope during their loved one's cancer experience by finding "comfort in faith," "meaning and purpose," and "connecting with God" (p. 31).

### *Positive Emotion*

Prevention of psychological and physical illness is the foundation of positive psychology. Thus, instead of focusing on decreasing negative symptoms once the pathology begins, positive psychology focuses on enhancing individual strengths before the symptoms commence (Berman & Davis-Berman, 2005). Positive psychology encourages positive ways of living in its preventive efforts. For example, individuals foster long-term mental health and enhanced quality of living when they think rationally and insightfully and when they attend to the virtues of courage, hope, forgiveness, and perseverance (Ingram & Snyder, 2006). As positive psychology works with more long-term forms of psychotherapy, for instance cognitive therapy, its preventative nature may augment the maintenance of the therapeutic gains (Ingram & Snyder, 2006). When health professionals use preventive maintenance, it ultimately enhances patient and caregiver resilience and QOL.

### *Benefits in General*

Positive thinking has many important psychological and physical implications for the mental health field. For example, positive thoughts affect emotional states and physiology, which may affect the commencement of a disease and its progression and course (Taylor et al., 2000). Positive beliefs may also promote better health behaviors. According to Taylor et al. (2000), individuals who exhibit a positive sense of self-worth and an increased sense of self-efficacy and who are optimistic about the future are more cautious about their health practices and more likely to utilize available services. Accumulated positive emotions augment psychological and intellectual resources and help individuals feel good long-term (Fredrickson & Joiner, 2002, p. 175). Positive emotions help to buffer the negative effects on physical health caused by the negative physiological consequences associated with the emotional experience (Salovey et al., 2000).

### *Benefits in Stressful Situations*

Under stressful conditions, individuals may be less likely to engage in health-promoting behaviors and more likely to get caught in a downward spiral that fuels depression, negative emotion, and pessimistic thinking (Fredrickson & Joiner, 2002). Kelsey et al. (2006) examined 1,093 blue-collar women from diverse backgrounds in order to delineate the relationship between positive affect and self-reported health and health behaviors. Positive affect related to better self-rated health and increased levels of

exercise and was a better predictor of physical health symptoms than negative affect. Furthermore, Kelsey and colleagues reported a relationship between positive coping strategies (e.g., using relaxation exercises, prayer, and social support) and the likelihood of exercise. Positive emotions promote physical health and facilitate healthy behaviors.

### *Benefits in Terminally ill Patients*

It is possible that positive thoughts and emotions lead to a more positive behavioral environment in patients and caregivers. Reed, Kemeny, Taylor, and Visscher (1999) demonstrated prospectively that expectancies, confidence, optimism, and a sense of personal control made a positive difference in a sample of 72 asymptomatic terminally ill HIV-positive men living in California. Reed and colleagues found that, even in the face of losing dear friends to the illness, positive expectations regarding one's future health status, feelings of confidence and optimism, and a greater sense of control over the illness were all associated with a slower progression of HIV-related symptoms. This demonstrates the profound power that one's thoughts have on the body. This also has implications for patients in challenging situations. It appears that over time, positive or negative thoughts will affect physical health, emotions and mood, and overt behavior (Berman & Davis-Berman, 2005).

### *Benefits in Caregivers*

Due to the demands of the caregiver and patient relationship, this relationship can be considerably more stressful on the caregiver than it is on the terminally ill patient. However, optimistic and self-efficacious caregivers tend to be more successful in their coping efforts, resulting in lower stress levels. In a study conducted by Hulbert and Morrison (2006), optimism correlated with higher self-efficacy, lower perceived stress, and higher satisfaction and social support in their small sample of caregivers of terminally ill patients.

### *Religiosity and Spirituality*

Over the years, the terms *religiosity* and *spirituality* have assumed many definitions, and the distinctions between what religiosity and spirituality actually mean have historically been convoluted and unclear. The ambiguity of the terms has posed a theoretical challenge to researchers and professionals (Cohen & Koenig, 2003). Researchers and clinicians often misuse religiosity and spirituality by mistaking one term for the other and by interchanging the meanings. Historically, intertwining religiosity and spirituality did not pose a problem, and only recently have researchers begun to separate the two meanings from one another (George, Larson, Koenig, and McCullough, 2000). It is important to understand that religion and spirituality are two very different experiences that share a similar sacred core. Both spirituality and religiosity focus on the sacred or the divine, including beliefs about the sacred and the effects of those beliefs on behavior

(Wulff, 1997). Spirituality and religiosity have similar practices used to attain a sense of the sacred (George et al., 2000, Wulff, 1997), spiritual identity, social support, life meaning, life satisfaction, and a sense of hope and enhanced coping (Reyes-Ortiz, 2006). Diagrammatically, spirituality encompasses religion and the sacred.

### *Benefits in General*

Religious involvement provides numerous benefits to individuals in general, to medical patients, and finally to caregivers and ALS patients. Generally, religious involvement provides a form of capital on which individuals can draw in time of need to overcome problems, carry out specific behaviors, or garner strength (Curlin, 2004). Furthermore, religion provides other important advantages to individuals who utilize the resources. First, religious involvement provides psychological advantages, which helps to change an individual's state of mind and has been associated with optimism and hopefulness. Second, religious involvement provides social advantages through religious communities, church affiliation, and joining in a common cause against engaging in negative or harmful behaviors or in worshipping together (Curlin, 2004). Finally, religious involvement provides individuals with spiritual advantages and resources that derive from a transcendent source or even from the privacy of prayer (Curlin, 2004).

*Satisfaction and well-being.* Religious and spiritual activities may have an effect on perceived health status. Generally, religious beliefs and participation correlate with positive self-perceptions and emotions, greater self-esteem, and happiness. In a recent

study conducted by Zullig, Ward and Horn (2006) in a sample of 1,000 college students, they found a significant correlation between students who described themselves as spiritual (or religious) and greater self-perceived health. Accordingly, self-perceived health influenced students' life satisfaction for both female and male participants in the sample. Koenig et al. (2001) suggested that religious beliefs may also foster feelings of self-worth and overall healthier views of the self by discouraging excessive pride, self-condemnation, and the engagement in unhealthy behaviors.

*Happiness and longevity.* Positive psychological states have a powerful effect on physical functioning and health outcomes. Researchers suggest that optimism, in particular, is associated with healthier immune systems (Segerstrom et al., 1998), and religiosity may be associated with higher immune system functioning because life satisfaction tends to increase happiness and health and overall longevity. Accordingly, Koenig, Kvale, and Ferrel (1988) examined the connection between religion (Hoge Intrinsic Religiosity Scale) and life satisfaction/morale (Philadelphia Geriatric Morale Scale) in a sample of 836 adults over the age of 60 living in the midwestern United States. Koenig and collaborators found that participants who frequently attended church, prayed, or read the Bible or who more deeply committed to their faith experienced significantly higher levels of well-being than less religiously involved individuals. Koenig and colleagues found the same result regardless of age, race, sex, physical health, financial status, or level of social support.

*Mental health.* There may be a relationship between spirituality and mental health outcomes. Satisfaction with life may decrease the incidence of mental disturbances. Most of the adult population has suffered from depression or anxiety of varying degrees at some point in their lives. Many individuals have difficulty solving their problems on their own and require outside assistance (Koenig, 1997). According to Frisch and colleagues (2003), lower life satisfaction correlates with anxiety, depression, somatoform disorders, suicide, and overall decreased longevity. Koenig, Cohen, Blazer, and Krishnan (1995) followed, for an average of 6 months, 202 medically ill patients discharged from a Veterans Administration hospital, to determine the connection among medical illness, mental health, and religious coping and to determine what patient characteristics predicted depression. Koenig and colleagues measured depression using the Hamilton Depression Scale and the Geriatric Depression Scale and religion using unstructured interviews (asking the patients what they did to cope and if they used religion to cope). Results indicated that the main predictor of mental health status (i.e., decreased depression) over 6 months was not social support from family or friends, physical health status, or income/education level, but rather the extent to which patients relied on their faith or religion to cope.

*Physical capability.* Religion may also correlate with better physical health, both directly and indirectly. Religious individuals may pay closer attention to their bodies and place value on health and healing. For example, the Christian religion places value on “the temple of the Holy Spirit” (Koenig, 1997, p. 108); Mormon religious doctrines encourage abstinence from alcohol, cigarettes, caffeinated drinks, any habit-forming

drugs, and highly processed foods (Koenig et al., 2001). Buddhists follow a modern vegetarian diet high in carbohydrates and low in saturated fat. Individuals who follow a Jewish doctrine avoid pork and alcoholic beverages and adhere to a kosher diet (Koenig et al., 2001) to promote health and well-being. When individuals pay closer attention to their bodies, they are more likely to engage in early disease detection and adherence to treatment (Koenig, 1997). In addition, religiously active individuals make a commitment to abstain from engaging in an excess of adverse behaviors (e.g., smoking, risky sexual behavior, drinking and drug use; Koenig, 1997). According to Daaleman and Kaufman (2006), the threat to an individual's health or functional status promotes gathering and processing of information and interpreting and meaning-making. Accordingly, spirituality is helpful in reframing an illness for individuals and in providing meaning to experiences. Thus, Daaleman and Kaufman found greater spirituality to be inversely and independently associated with depressive symptoms in 509 primary care outpatient participants.

*Social support.* Religion indirectly enhances a sense of community by providing individuals with a stronger social support network. Social support systems may encourage healthy behaviors (e.g., treatment compliance) and discourage unhealthy and risky behaviors (e.g., smoking, drug use, risky sexual behaviors). Friends tend to provide a sense of belonging. Social behaviors may increase an individual's will to live and overall survival time (Koenig, 1997). Zuckerman, Kasl, and Ostfeld (1984) longitudinally examined the predictors of mortality in 400 severely ill elderly patients. They found that more religious participants survived longer, even when accounting for health and sex



characteristics. In their 2-year study, only 19% of religious men and 11% of religious women died, whereas 42% of nonreligious men and 20% of nonreligious women died.

Expanded social networks tend to decrease feelings of depression. Idler (1987) found an association between greater religiosity and lower levels of functional disability and depressive symptoms in a sample of 2,811 elderly patients. Interestingly, Idler reported a correlation between increased church attendance (i.e., public religiosity) and decreased physical disability and depression in women. Among the male sample, Idler reported a correlation between increased private religiosity (minimal public religiosity) and decreased physical disability and depression. The differences in the sexes may be due to the way in which men and women cope with problems (women seek social interactions, and men tend to be more private with feelings).

Social support may also increase an individual's resilience, adaptability, and positive emotions. For years, social and evolutionary psychology recognized the patterns of social animals and humans and the context in which a group promotes survival (Myers, 2000). It is important to attach to others, to define a "we" within a family and friend network, and to have a teamwork mentality to prevent vulnerabilities to illness and stress (Myers, 2000). According to Salovey et al. (2000), there is a reciprocal relationship between social support and the experience of emotions. For example, it makes sense that an individual's emotional state influences the need for and the reception of social support, just as social support influences an individual's existing emotional state (Salovey et al., 2000). Taylor et al. (2000) suggest that optimistic and self-confident individuals who exhibit a sense of personal control may have more opportunities for social support or more resources to gain that support in times of crisis.

### *Benefits for Medical Patients*

*Lowered death anxiety.* Regardless of religious affiliation, the religious doctrine provides a framework for understanding the human existence of death and dying for patients, family members, and health care professionals. Many world religions believe in life everlasting, including Christianity (“born again”), Hinduism (some return to the womb; others return to another body), and Buddhism (at death, you become aware that there is no death). Therefore, religious beliefs should be associated with a decreased fear and greater acceptance of death (Daaleman & Vandecreek, 2000). Individuals who have a positive psychological state or engage in religious activities may exhibit increased longevity. However, for some religious individuals, death may not be something that they fear, but something that they face with pride and dignity and even, perhaps, anticipation (Cohen & Koenig, 2003). Believing in life everlasting may help terminally ill patients to cope with what is to come. For example, Cartwright (1991) found 78% of dying adults ( $N = 639$ ) who believed in life after death found their faith helpful during the dying process. Thorson and Powell (1990) found a negative association between both age and religiosity and death concerns in a group of 346 participants whose ages ranged from 18 to 88. Overall, Thorson and Powell concluded that people feared the process of dying more than death itself; hence, the researchers identified religion as an important moderator in their study. Similarly, Murphy, Albert, Weber, Del Bene, and Rowland (2000) found that spiritually inclined ALS patients ( $N = 49$ ) reported fewer thoughts of death and less concern about what would happen after death.

Medical professionals should pay attention to patients and talk with them about their mortality. Ehman, Ott, Short, Ciampa, and Hansen-Flaschen (1999), studied a sample of 177 adult ambulatory patients and found that 77% believed in life after death, 90% believed that prayer may sometimes influence recovery from an illness, and 45% agreed that spiritual or religious beliefs would influence their medical decisions if they became gravely ill. It is likely that most chronically ill patients will feel similar forms of discomfort, helplessness, and pain; however, the hope of an afterlife for religious patients provides comfort to them and to their families (Ehman et al., 1999). Accordingly, Ehman and colleagues reported that 66% of patients indicated a desire for physicians to discuss spirituality or religiosity issues with them because it strengthens trust in the relationship and makes difficult end-of-life decisions easier.

*Quality of life.* Medical professionals, patients, and caregivers have learned about coping with ALS from other terminal diseases. Studies on ALS correlate religiosity and spirituality with increased hope, increased adaptation to the disease, a lessened fear of death (Murphy et al., 2000), and higher QOL (Bello-Haas et al., 2000). According to Murphy et al. (2000), a life-threatening crisis affects faith development in many different ways: (a) by providing a new perspective on life and a new expression of faith, (b) by giving the individual a new conceptualization of God, and (c) by providing a new view of the self and of others.

Research in HIV/AIDS demonstrated that the commencement of a terminal illness likely leads to an individual's faith being "stronger" or "more real" (Courtenay, Merriam, & Reeves, 1999, p. 207) or to an individual seeking comfort religiously or spiritually

(Murphy et al., 2000). Facing a terminal illness may also give an individual a sense of purpose, such as to help others (Murphy et al., 2000). In a similar study conducted by Szaflarski et al. (2006) with 450 HIV/AIDS patients, spirituality and religiosity associated positively with a greater level of overall well-being, hope, and psychological adjustment, as well as a perception of life improvement since diagnosis.

There has been increased recognition of the importance of QOL among patients with a life-threatening illness, such as advanced cancer. Some authors make a connection between faith and hope. For example, Roberts, Brown, Elkins, and Larson (1997) found that as many as 93% of women diagnosed with gynecologic cancer, and who practiced a prior faith, developed hope during their illness. Furthermore, according to a study conducted by Ebricht and Lyon (2002), females with elevated hope scores on the Herth Hope Index reported less anxiety and fear about their disease.

*Social support.* Social support buffers the negative impact of stressful events, prevents the onset of depression, and speeds the recovery process from a number of physical and psychological problems. Social factors tend to act as mediators between life situations and the onset of emotional disturbances through immune system functioning (Koenig et al., 2001) and may prevent deterioration of functioning in chronically ill medical patients. Additionally, social isolation may increase emotional distress, which leads to physiological changes that negatively impact immune system functioning. This is consistent with findings from a study conducted by Levy, Herberman, Lee, Whiteside, Kirkwood, and McFeeley (1990) on a sample of 66 women with stage I or stage II breast cancer who had either lumpectomies or mastectomies. Levy and colleagues reported that

women with higher social support had greater NK cell activity (a measure of immunocompetence) than those with lower social support.

Social support relates to health and well-being in terminally ill patients. More recent studies compared 28 current and former spousal caregivers of Alzheimer's disease patients with 29 control participants (Esterling, Kiecolt-Glaser, & Glaser, 1996). Esterling and collaborators found a positive correlation between NK cell activity and both increased emotional support and tangible social support. In a similar study by Koenig et al. (2004), increased religiosity and spirituality consistently predicted greater social support in a sample of 838 geriatric medically ill patients. Koenig and colleagues suggested that religious and spiritual practices influence public sociability through church attendance and other religious meetings in mobile individuals. However, in less mobile individuals, religious and spiritual practices continue to influence social support and private life experiences, perhaps through an internalization of the religious experience, which influences one's perception of relationships (Koenig et al., 2004).

*Locus of control.* Medically ill individuals often feel out of control when afflicted with an illness that will ultimately take their lives. Religion may be especially important when stress from the illness gradually takes away the individual's sense of control and mastery (Koenig et al., 2001). Religion may also help to restore empowerment and lead to a reappraisal of the crisis for the individual and/or the family. Religious or spiritual individuals believe that God is a loving and caring Father with a master plan; faith, as a means of coping with distress, is a form of empowerment (Ai, Peterson, Rodgers, & Tice, 2005). God is omnipresent; he is powerful, in control, and responds to prayer (Koenig et

al., 2001). By praying to a higher power, religious individuals feel that they can influence their situation by exerting control, facilitating adaptation, or growing personally in their faith. By depending on a higher power to control the situation, many religious individuals worry less about stressful situations and their outcomes (Koenig et al., 2001).

Control and faith are multidimensional phenomena. According to a study conducted by Ali and colleagues (2005) with a sample of 224 geriatric cardiac patients, general subjective religiosity was inversely associated with internal health locus of control; however, the specific activity of prayer was positively associated with health locus of control. Prayer may play the role of a coping strategy for individuals who see an illness or a crisis as uncontrollable, and it may restore control to the situation. Moreover, personality influences an individual's perceptions of situations. Schottenbauer, Rodriguez, Glass, and Arnkoff (2006) explored the differences in personality dispositions during exposure to high- and low-control situations in a randomly chosen group of individuals. The researchers discovered that positive disposition (i.e., interested, attentive) tended to buffer an individual's negative perceptions of situations over which the individual has little control. Similarly, negative affectivity, trait anxiety, and pessimism indicated a negative dispositional construct, which predicted negative religious coping. Essentially, positive disposition directly predicted positive religious coping, and negative disposition (distress, hostility) predicted negative religious coping (Schottenbauer et al., 2006).

*Medical compliance.* Religious beliefs may help medical patients make sense of their illness and integrate health changes into their lives more easily. This may be one

reason why religious individuals comply with medical treatment at a higher rate than nonreligious individuals. Koenig et al. (2001) noted a few additional hypotheses for this relationship: (a) religion's impact on the patient's belief system about the cause of the illness, (b) patient's belief about his/her ability to cope with the illness, and (c) patient's availability of a social support network. According to Koenig and colleagues, many patients believe in naturalistic mechanisms of disease and, thus, they use spiritual treatments to complement traditional medicinal methods. Furthermore, individuals who practice religious or spiritual activities tend to cope better with both physical and psychological illnesses and have more fulfilling support systems. Church members may provide transportation, encouragement, and help to increase medical compliance, positive beliefs, optimism, and hope. Finally, religious individuals may be more compliant with treatment because of a general attitude toward compliance. According to Koenig and colleagues, religious individuals tend to be low risk-takers and to hold more conservative values, follow societal rules, and adhere to the advice of authority figures.

*Optimism and hope.* Researchers suggest that humans are optimistic by nature (Fournier, Ridder, & Bensing, 2003), and according to the optimistic bias (Armor & Taylor, 1998), terminally ill individuals report experiencing fewer negative events than individuals among the general population. However, feelings of hopelessness, depression, and a loss of control are common reactions for individuals when they approach the terminal phase of an illness, and many people, when faced with adversity, feel vulnerable and stripped of the illusion of control. According to Taylor (1989), the feeling of loss of control that occurs when an individual faces a terminal illness is only temporary and, for

the most part, as stated in the cognitive adaptation theory, motivates that individual to seek ways to restore the initial levels of optimistic beliefs and feelings of control over the situation. For example, some patients cope with feelings of death by reframing their negative thoughts and by surrounding themselves with family and friends; however, other patients feel the sense of despair that accompanies the final months or weeks of life (Koenig et al., 2004; McClain et al., 2003). To explain the impact of positive thinking and efficacy on physical illness, Fournier et al. (2003) conducted a study with diabetes mellitus patients ( $n = 90$ ), MS patients ( $n = 90$ ) and healthy controls ( $n = 60$ ) and found that the perception of illness did not affect the individual's view of efficacy or positive outcome expectancies unless the patient suffered from severe depression. Therefore, it appears that remaining optimistic in light of an ALS diagnosis is critical to slowing the progression of the disease.

With the pervasiveness of psychological and physiological distress, development and maintenance of spiritual well-being may be crucial to coping effectively with a life-threatening illness. O'Connor et al. (1990) found 30% of their sample of 30 cancer patients relied on God or religion as a source of hope during their illness; these patients felt that the cancer was God's plan for their life, and they accepted it faithfully. More recently, McClain and colleagues (2003) conducted open-ended interviews with 160 patients in order to assess the relationship between spiritual well-being, depression, and end-of-life despair in terminally ill cancer patients. The researchers found significant correlations between spiritual well-being and desire for hastened death, hopelessness, and suicidal ideation. According to McClain et al., spiritual well-being strongly predicted each of the outcome variables and offered protection against end-of-life despair (2003).



Essentially, researchers consider the traits of positive affectivity, optimism, and hope to be desirable and adaptive, whereas negative affectivity, pessimism, and trait anxiety were not effective in every situation (Schottenbauer et al., 2006).

### *Benefits for Caregivers*

*Health and well-being.* Caregivers who engage in religious or spiritual activities may be healthier behaviorally, socially, psychologically, and physically. For instance, religious individuals tend to be less likely to use drugs and alcohol (Leblanc, Driscoll, & Pearlin, 2004). Additionally, spiritual or religious groups foster supportive communities and offer coping strategies that help individuals make decisions, engage in relaxing activities, and find meaning in stressful circumstances (Leblanc et al., 2004).

*Enhanced coping.* It is important to understand how religion affects the caregiving experience and the well-being of caregivers for the health and well-being of the patient. Religion may provide caregivers with the strength to be optimistic and self-efficacious, as well as with a way to derive meaning or purpose, hope, and a sense of control over the situation (Pearce, Singer, & Prigerson, 2006). In support of this, Chang, Noonan, and Tennstedt (1998) conducted a study on 127 caregivers of elderly persons with disabilities in order to explore adjustment, religion, and relationship with the care recipient. The researchers found that caregivers who used religious or spiritual beliefs coped with caregiving stressors in an effective manner and had a better relationship with care

recipients, lower levels of depression, and better self-care (i.e., less submerged in the caregiving role).

*Personal growth and satisfaction.* A positive attitude tends to be helpful to caregivers, and a negative attitude tends to be hindering. According to Theis et al. (2003), both the caregiver and the patient found a positive attitude of the other person helpful while going through the disease process. For example, one caregiver mentioned what helped her with getting by. “I guess my attitude. She took care of me and now it’s my turn to take care of her. She wants to cooperate” (Theis et al., p. 52). Furthermore, Morano and King (2005) suggested that religiosity was a partial mediator of problematic behavior on the caregivers perceived self-acceptance. Moreover, it appeared that as religiosity increased in the sample of 384 Alzheimer’s disease caregivers, so did their perception of self-acceptance (Morano & King, 2005). It appears that religiosity may be linked to caregiver self-acceptance, which is influenced by the meaning that caregivers attach to the experience. Therefore, religious support is an important protective factor for caregivers and, most likely, should be incorporated into their lives.

*Adjustment.* Outcomes of religious studies on coping indicate that religiosity among caregivers is linked to enhanced adjustment. According to Theis et al. (2003), two overarching themes persist in the caregiving literature with regards to coping including the use of formal religion and social support, and again in finding meaning in the caregiving experience including having a positive attitude and reframing negative events. For example, in a longitudinal study of 62 caregivers of persons with Alzheimer’s disease

or cancer, Rabins, Fitting, Eastham, and Zabora (1990) found that strength of religious belief at baseline was associated with better emotional adjustment among caregivers at 2-year follow-up, even when researchers controlled for personality variables, family functioning, and levels of anger and guilt.

*Self-efficacy.* According to Bandura (1994), self-efficacy is an individual's perception of how he/she can impact the circumstances/events in his/her own life. Caregivers who display confidence and mastery may be more likely to maintain a harmonious relationship with the terminally ill patient, remain more optimistic, and handle stressful situations more effectively (Gottlieb & Rooney, 2004). Emotional distress highly impacts caregiving resources and mastery/optimism appears to buffer much of this distress for caregivers (Gaugler, Hanna, Linder, Given, Tolbert, et al., 2005). Murray-Swank et al. (2006) found that personal religiosity associated positively with level of mastery ( $r = .26$ ) and self-care ( $r = .33$ ) and negatively with level of depression ( $r = .25$ ) in a sample of 83 caregivers. Pearce and colleagues (2006) also found a strong association between negative religious coping strategies (e.g., feeling abandoned by God) and poorer adjustment in their sample of 162 informal caregivers who, in turn, exhibited decreased optimism, self-efficacy, and less perceived social support. Gottlieb and Rooney suggest that caregiver performance and mental health may be associated more with a sense of mastery and coping than with stress level (Gottlieb & Rooney, 2004).

*Quality of life.* Given the psychological, physical, social, and financial demands that accompany taking care of a chronically ill patient, religious support appears to be one of the most important aspects of successful caregiving (Weaver & Flannelly, 2004). Religious caregivers may feel more positive about their role as caregivers and may create positive interactions with patients (Weaver & Flannelly, 2004). Quality of caregivers can significantly influence patient QOL; therefore, it is essential to underscore caregiving coping and its connection to QOL in the literature.

*Social support.* Caregivers of patients with Alzheimer's disease struggle with making sense of the situation, and they search for meaning in the convoluted experiences many face in taking care of loved ones. A study conducted by Paun (2004) revealed that all caregivers in the study sample ( $N = 14$ ) found that aspects of their lives were touched in a spiritual way. For example, the entire sample, although small, found it comforting to maintain contact with a church, either by attending weekly services or by reading the church newsletter. Black caregivers tended to create an ongoing commentary with their higher power and sought to find meaning in the situation, whereas, White caregivers coped with the situation through an altruistic means and by accepting their situation. A caregiver stated, "I'm trying my best and put all my trust in God, because man will fail you, but not God" (Paun, 2004, p. 15).

### *Benefits for ALS Patients*

*Physical functioning.* It is important to not discount patients' physical functioning as they experience the process of ALS. Physical functioning, along with caregiver's

religiosity and spirituality, as measured by various scales of the Brief Multidimensional Measure of Religiosity/Spirituality (BMMRS), may predict patients' negative emotions, above and beyond their own religiosity and spirituality. According to a study conducted by Bremer et al. (2004), ALS patients continued to maintain positive self-perceptions despite physical health deterioration. Additionally, over time, researchers found a significant correlation between self-perception of health and religiosity and QOL. Neudert et al. (2004) concurs that despite the severe and progressive paralysis in muscle functioning that a significant proportion of patients experience with ALS, many patients continue to report a higher level of personal and psychological well-being. For this reason, it may be important to focus on the patient's own subjective description of QOL, rather than a preconceived formulation that may be a very different experience for every individual.

*Quality of life.* ALS challenges aspects of the individual's functioning, including social, psychological, and spiritual well-being. Bello-Haas and colleagues (2000) reported that 86.4% of their ALS patient sample ( $N = 60$ ) practiced a religion, with 44.8% attending weekly worship services. Additionally, 60% indicated that they engaged in one or more of the following spiritual activities: (a) praying, (b) watching televised worship services, (c) receiving communion, (d) reading the Bible or engaging in Bible study, (e) engaging in fellowship, (f) having a pastor visit their home, or (g) practicing meditation. Overall, Bello-Haas and colleagues found that individuals who practiced more religiously (i.e., higher religious well-being scores) had a higher QOL (i.e., lower Sickness Impact

Profile). This indicates that there may be a relationship between religiosity and QOL in ALS patients.

*Hope.* Religion may not offer a cure to terminally ill patients, but it may offer hope to individuals who attempt to adapt to a grave prognosis. Religious or spiritual views may provide individuals with a framework for the interpretation of events (Murphy et al., 2000). According to George et al. (2000), religion provides coherence and meaning for the interpretation of difficult events. Religion helps people understand “their role in the universe, the purpose of life, and develop the courage to endure suffering” (George et al., 2000, p. 111). Moreover, Murphy et al. (2000) reported a significant relationship between the Beck Hopelessness Scale and levels of religiosity ( $p < .04$ ) and spirituality ( $p < .05$ ) in a sample of 46 ALS patients. It appears that the more religiosity or spirituality patients exhibited, the more hope they reported feeling.

*Locus of control.* When individuals face a life-threatening illness, it often causes feelings of hopelessness and increased vulnerability, both of which may inevitably influence the course of the illness. A diagnosis of a terminal illness is akin to a crisis, and many times, patients will experience similar feelings and emotions. Plahuta et al. (2002) investigated the relationship of psychosocial factors to the presence of hopelessness among 136 ALS patients. Plahuta and colleagues discovered that ALS patients with an external locus of control harbored cognitive distortions that led to feelings of hopelessness (i.e., negative expectations about the future). For example, specific health-related locus of control (HLC) scale items, such as, “I can only do what my doctor tells

me to do,” or “No matter what I do, if I am going to get sick, I will get sick,” demonstrated cognitive schemas representative of an external locus of control orientation (Plahuta et al., 2002). Interestingly, there was no relationship between hopelessness and illness characteristics, such as physical functioning, length of disease, and disease severity among ALS patients (Plahuta et al., 2002). What is most important to emphasize from these findings is that external locus of control and lack of meaning in life are more predictive of hopelessness in ALS patients than decline in physical functioning. Thus, by increasing patients’ and caregivers’ internal locus of control and purpose and meaning, they might experience more satisfaction with life as they experience the process of physical decline in ALS.

### *Religiosity and Spirituality as Coping Strategies*

There has been growing interest in religion as a coping resource in the past decade. In order to assess an individual’s true coping resources, researchers must use open-ended questions, such as, “What enables you to cope with the difficulty of stressful events in your life?” When researchers formulate questions in other ways, the numbers of individuals who endorse using spiritual and/or religious means for coping tend to be inflated (McGrath, 2003). This overrepresentation is commonly due to the *social desirability principle*, which claims that individuals behave or think in ways that are desirable to others (Koenig, 1997). Perhaps the “proper” responses to the question “How do you cope during illness?” are thought to be prayer, spirituality, and relying on a higher power. For this reason, open-ended questions provide the most accurate information. In

light of this, many of the studies reviewed above may have inflated the use of the religiosity and spirituality as coping mechanisms for ALS patients and caregivers to find meaning and satisfaction in their disease. Thus, it is important to keep this possible reporting error in mind throughout the current study, as it is a limitation that will be addressed later in this document.

### *Positive/Negative Coping*

Religious coping can be divided into types: positive and negative coping. According to Pargament, Koenig, and Perez (2000), positive religious coping includes a variety of methods that generally involve aspects of social support and positive cognitions and usually result in beneficial outcomes (e.g., turning to God or fellow worshipers for support and strength). It also involves a sense of spirituality, security in a relationship with God, and connectedness with others (Miller, McConnell, & Klinger, 2007). On the other hand, negative religious coping refers to an association with negative attributions, cognitions, and outcomes (e.g., discontent with God; Pargament et al., 2000). It also represents a less secure relationship with God, a tenuous view of the world/others, and a search for meaning (Miller et al., 2007).

How an individual appraises and chooses to respond to a stressful situation is called *coping style* (Brennan, 2001). There are several coping frameworks to distinguish religious coping mechanisms. Fabricatore, Handal, Rubio, and Gilner (2004) discussed the following frameworks, based on the ways in which individuals approach problematic situations: (a) *deferring approach*, in which individuals take a passive role in coping with



the illness and believe that God is in control of what happens; (b) *collaborative approach*, in which individuals approach the coping process as a partnership with God and believe that they share the responsibility for problem solving with God; and (c) *self-directing approach*, in which the individual believes that God has given them the necessary skills and means with which to actively cope. Fabricatore and colleagues found that collaborative religious coping mediated the relationship of religiosity to well-being and distress in a sample of 175 undergraduate students.

### *Shared Faith*

Shared religious affiliation may help to decrease isolation and facilitate supportiveness for both patients and caregivers in a time of chaos and confusion. Individuals with life-threatening illnesses draw strength from their families and from their communities. Often, this connection helps terminally ill individuals to cope by feeling a sense of meaning, love, value, and purpose, as well as a connection to the social world (Murray, Kendall, Boyd, Worth, & Benton, 2004).

The sharing of faith, prayer, and fellowship between caregivers and patients allows each individual to derive strength from a similar experience (Murray et al., 2004). Furthermore, according to Murray and colleagues, nonspiritual/nonreligious individuals have the opportunity to share in other coping strategies, such as lighting candles or watching television together. In a study conducted by Taylor (2006), family caregivers ( $n = 68$ ) and patients with cancer ( $n = 156$ ) who shared religious and spiritual beliefs expressed similar spiritual interests (e.g., maintaining a positive outlook about the illness,

willingness to give love to others, ability to find meaning in grim circumstances, and relating with God). Taylor (2006) found that religious individuals considered their spiritual needs to be important, and they were able to ask for help with those needs. Forty-four dyads who displayed conflicting perceptions with regard to QOL issues continued to remain positive, in light of myocardial infarction recovery, as long as at least one member of the dyad retained a positive appraisal of the situation (Miller et al., 2007). According to Bremer et al. (2004), it is important to focus on QOL needs and religiosity when patients and caregivers face a terminal illness. Likewise, Bremer and colleagues found that as ALS progressed, patients' religious practices strongly predicted their QOL.

Prayer is one religious behavior that caregivers and patients report as helpful. Theis et al. (2003) noted that caregivers and care recipients will often pray for each other. Additionally, reading the Bible is another coping mechanism that reportedly helps patients and caregivers who can no longer go to church because of limited physical function and caregiving demands. Additionally, results of a meta-analysis conducted by Ano and Vasconcelles (2005) indicated that individuals who used religious coping strategies, such as compassionate religious reappraisals, collaborative religious coping, and spiritual support seeking from others, learned better ways to handle future stressful situations and experienced more positive affect and higher self-esteem.

### *Cognitive Appraisal*

All individuals at some time over the course of their lives will face stress. Religion may provide a cognitive framework that enables a healthy appraisal of the

stressors. Moreover, religion attempts to provide individuals with a coherent and meaningful worldview as well as a framework to interpret events in a way that is more optimistic and less threatening to the self (Koenig et al., 2001). According to Koenig et al., (2001) religion provides a focus outside of the individual, and it discourages excessive preoccupation with the self and one's personal needs. Accordingly, when personal identity and self-esteem become rooted in both the individual and the faith community, the individual is better prepared to detach from material possessions (e.g., physical appearance, talent, productivity) when they are lost. Self-esteem and identity gained from religion and spirituality provide happiness when the loss actually occurs (Koenig et al., 2001).

It may be that having a relationship with God influences one's appraisal of a crisis. Religious resources may also have an association with cognitive appraisals in such a way that it influences an individual's general coping. For example, breast cancer patients ( $N = 52$ ) who believed in God reframed their illness in such a way that it became positive and gained some remote importance or meaning in their life (Gall, 2000). Additionally, religious resources, rather than nonreligious resources, predicted emotional and spiritual well-being for the sample of long-term breast cancer survivors (Gall, 2000).

A common theme throughout the literature on chronic illness is the view that a life-threatening illness intensifies an individual's search for meaning. Koenig et al. (2001) state that religious and spiritual individuals tend to have greater purpose and possess greater hope and optimism, meaning, and a sense of coherence. Belief in a purposeful Creator who has a plan and a will for humanity may provide terminally ill individuals with a decreased sense of death anxiety (Koenig et al., 2001; Thorson & Powell, 1990) and an increased meaning and purpose in life. Consistent with the coping literature, and in light of the fact that caregivers and patients spend many hours together

throughout a day, both caregivers and patients need to engage in active problem solving and not passive coping strategies.

### *Assessment of Religious/Spiritual Coping*

Using an open-ended interview format, researchers learn about differences in medical patients' beliefs with regard to religiosity and spirituality when facing death. For example, in a comprehensive study conducted by McGrath (2003), the researcher interviewed 14 hospice patients in order to determine whether individuals embrace religious beliefs when faced with the challenges of a terminal illness. McGrath (2003) found three common reactions: (a) most patients did not seek religious comfort as a response to the life-threatening illness for a variety of reasons, (b) some patients actively turned away from previously held religious beliefs because of "family pressure to embrace religion" (p. 888), and (c) a few patients felt that the illness strengthened their existing religious beliefs. Furthermore, most of the participants in the sample either did not have religious beliefs or operated by their own belief system; only 3 of the 14 participants endorsed adhering to a clearly defined religion that became strengthened during the illness (McGrath, 2003).

### *Positive Emotions as Coping and Connection to Faith*

The primary association between positive emotions and religiosity and spirituality in terminally ill patients and caregivers is the underlying power of each as a coping strategy for dealing with the chronic disease process. Hope is a set of schemas that helps individuals gain a sense of goal-directed determination and an ability to conceptualize goals clearly, generate multiple pathways toward goal pursuit, exhibit motivation to pursue goals, and generate and carry out plans to achieve goals (Stanton, Danoff-Burg, & Huggins, 2002).

There is a complex relationship between hope and coping, which affects the process of adjustment to terminal illness. A study conducted by Stanton and colleagues (2002) revealed that oncology patients ( $N = 70$ ) with increased hope tended to adjust at a quicker rate over the first year of breast cancer diagnosis. It is possible that an early acceptance of the disease prepares individuals for “active” coping and problem solving because they tend to be more hopeful and exhibit the pathways and agencies (e.g., motivation and resources) to deal more effectively with the upcoming stressors. In addition, Stanton and colleagues found an association with hope and various coping strategies (e.g., reinterpreting positively, turning to religion, coping in a problem-focused manner, seeking social support, and accepting the disease) among their sample. Religious coping was more useful for patients possessing lower hope because it provided them with an increased sense of control, meaning, intimacy, and belongingness. Generally, coping in a problem-focused manner (e.g., seeking information, finding resources, praying and asking a higher power for help/strength, and garnering support from others) increases hope, optimism, and acceptance of the disease process through the use of active coping strategies (Stanton et al., 2002). Active coping helps patients and family members

decrease the use of denial, avoidance, and rumination over “what might happen” or “what could happen.”

Individuals who actively practice religiosity or spirituality tend to be more physically and psychologically healthier and tend to live longer than individuals who do not. There is evidence that religious individuals exhibit healthier lifestyles, avoidance of alcohol and smoking, decreased stress, early detection of disease, and increased compliance with medical treatment. Some religious individuals develop social support through a sense of community provided by their church family. Medical professionals need to realize that religious and spiritual beliefs may be a significant source of strength for some patients and caregivers, and physicians should encourage those individuals to participate more actively in a faith community throughout the duration of the illness. Participation with others who share their belief may decrease loneliness and isolation and help patients and caregivers to cope better with the many stages of the illness. In essence, the presence of social support, psychological coping mechanisms, positive emotions and self-perceptions, and engagement in healthy behaviors are the most effective mediators between religion and health outcomes.

Many spiritual challenges accompany dealing with a terminal illness and can precipitate the search for meaning in the lives of patients and caregivers (Murray et al., 2004). Research supports the significance of involvement in religion in a patient's QOL and the ability to attach meaning to the news that the individual is dying (Bremer et al., 2004; Murphy et al., 2000; Robbins, Simmons, Bremer, Walsh, & Fischer, 2001). For example, patients may question God by asking “Why me?” or express a negative attitude about their situation, even when their caretaker is attempting to derive meaning

spiritually from the situation (Murray et al., 2004; Theis et al., 2003). Individuals may develop or strengthen a preexisting faith during times of crisis to help buffer the stress of the situation (Courtenay et al., 1999). Religiosity and spirituality can also produce feelings of guilt, self-doubt, or shame in the ALS patient and caregiver (Leblanc et al., 2004). The impact of a terminal illness can be a tremendously daunting experience for the patient and for the family; patients and caregivers can sometimes become hopeless when their lives lack meaning and purpose or when they have low self-efficacy (Plahuta et al., 2002).

## Research Questions and Hypotheses

### *Research Question 1*

What is the relationship between patient negative emotion and both patient religiosity and patient spirituality?

### *Hypothesis 1*

There will be an inverse relationship between patient negative emotion, as defined by the ALS Specific Quality of Life Questionnaire-Revised (ALSSQOL—R), and both patient religiosity, as measured by the Idler Index of Religiosity (IIR), and patient spirituality, as defined by the total score on the following indices of the Fetzer Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS): forgiveness

(religiosity/spirituality), daily spiritual experiences (spirituality), and overall self-rank (religiosity/spirituality).

### *Rationale for Hypothesis 1*

This is relevant to the current study because prior research indicates that medical patients and individuals who generally utilize religious and spiritual methods as forms of coping tend to have positive emotions, thoughts, and experiences.

### *Research Question 2*

What is the relationship between caregiver hope and both patient religiosity and patient spirituality?

### *Hypothesis 2*

There will be a direct relationship between caregiver hope, as defined by the Adult State Hope Scale (SHS) and both patient religiosity, as defined by the IIR, and patient spirituality, as defined by the total score on the following indices of the BMMRS: forgiveness (religiosity/spirituality), daily spiritual experiences (spirituality), and overall self-rank (religiosity/spirituality).

### *Rationale for Hypothesis 2*



This is relevant to the current study because hope and religion are both well-known coping responses for terminally ill patients and their caregivers. Caregivers who exhibit the schema set of hope will adjust more readily to the disease process and possess more problem-focused coping strategies aimed at increasing control, knowledge, resources, support, and confidence. This confidence (or lack thereof) will likely transfer directly onto the patient and influence his/her style of coping. For example, Borneman and colleagues (2002) published a study with 51 family caregivers who maintained a high level of hope during their loved one's cancer experience by finding "comfort in faith," "meaning and purpose," and "connecting with God" (p. 31).

### *Research Question 3*

What is the relationship between caregiver optimism and both patient religiosity and patient spirituality?

### *Hypothesis 3*

There will be a direct relationship between caregiver optimism as defined by the Life Orientation Test—R (LOT—R) and both patient religiosity as defined by the IIR and spirituality as defined by the total score on the following indices of the BMMRS: forgiveness (religiosity/spirituality), daily spiritual experiences (spirituality), and overall self-rank (religiosity/spirituality).

### *Rationale for Hypothesis 3*

This is relevant to the current study because of the well-documented relationship between optimism and religion (Pearce et al., 2006; Plahuta et al., 2002) and the underlying relationship with coping. Research indicates that religion is a positive form of coping that provides caregivers with strength to be optimistic and self-efficacious, as well as a way to derive meaning, hope, and a sense of control over the situation (Pearce et al., 2006). However, according to Pearce and colleagues, the opposite is also true: engaging in negative religious coping (e.g., blaming God) may lead to poorer adjustment, decreased optimism, self-efficacy, and perceived social support among caregivers of terminally ill patients. The caregiver-patient relationship is influential and interdependent. Caregivers who display confidence and mastery may likely maintain a more harmonious relationship with the terminally ill patient, remain more optimistic, and be able to handle stressful situations more effectively (Chang et al., 1998; Gottlieb & Rooney, 2004). A positive coping relationship that is reflective of optimism and utilizes religiosity and spirituality is likely to provide a sense of meaning, purpose, and direction for the patient.

### *Research Question 4*

What is the relationship among patient negative emotion and caregiver hope, caregiver optimism, caregiver religiosity, and caregiver spirituality?

#### *Hypothesis 4*

Patient negative emotion, as defined by the ALSSQOL—R, will be predicted by (a) caregiver hope, as defined by the Adult SHS, (b) caregiver optimism, as defined by the LOT—R, and (c) caregiver religiosity and spirituality, as defined by the total score of the following indices of the BMMRS: positive religious coping (religiosity), negative religious coping (religiosity), religious intensity (religiosity/spirituality), daily spiritual experiences (spirituality), and beliefs and values (religiosity/spirituality), over and above (a) patient physical functioning, (b) patient religiosity and spirituality, and (c) level of care provided by the caregiver.

#### *Rationale for Hypothesis 4*

This is relevant to the current study because religious and spiritual individuals tend to possess greater hope, optimism, purpose, meaning, and a sense of coherence (Koenig et al., 2001). Prior research indicates that when caregivers experience positive emotions, those emotions may have a significant impact on the behavior and belief systems of patients through a more positive relationship with patients. Patients and caregivers spend a significant amount of time together, and it is common for them to experience similar emotional states. Consistent with the coping literature, and in light of

the fact that caregivers and patients spend many hours together throughout a day, both caregivers and patients need to engage in active problem solving (i.e., positive coping) and not passive coping (i.e., negative coping) strategies to increase the likelihood of exhibiting positive emotions, self-worth, and efficacy. Furthermore, caregivers who exhibit increased mastery/optimism provide better care to the terminally ill patient.

### CHAPTER 3

## Method

There is a paucity of literature and research in the area of religious coping for caregivers of ALS patients in comparison to many other terminal illnesses. With ALS, much patient care focuses on multimethod interventions to improve individuals' QOL. Due to the progressiveness of and the immobilization caused by the disease, much of the responsibility falls on the patient's family and/or the spousal caregiver. There has been little attention to caregiver's needs or to the impact of the patient's disease on their loved ones. Similarly, there has been little attention to caregivers coping resources, especially the use of religiosity and/or spirituality and the impact of their use on the patient's QOL. It is time to consider the role of coping for caregivers, especially the use of religiosity and spirituality, and the effect of religious or spiritual coping on the QOL of ALS patients.

### *Study Design*

The current study used an exploratory analysis to examine the effects of caregiver religiosity and spirituality, caregiver positive emotions, and the effect of interdependent nature of the patient-caregiver relationship on the patient's psychological well-being. Therefore, the predictor variables in the study generally included caregiver spirituality, religiosity, hope, and optimism. The criterion measures, which are described elsewhere in this chapter, aimed to measure the ALS patient's QOL, as operationally defined by the patient's expression of psychological well-being.

The current study was structured around the use of archival data and was a cross-sectional study designed to test the hypotheses by utilizing data from a representative sample of ALS caregivers and patients in rural and suburban communities in central and southeastern Pennsylvania. The research utilized a series of bivariate correlations and a hierarchical multiple regression. Also, frequencies and descriptive statistics were used to describe caregiver personal characteristics. Demographic characteristics were summarized by calculating means and standard deviations for continuous variables, such as age. Frequencies were calculated for nominal or categorical variables, such as race, gender, length of caregiving, household income, or marital status.

### *Procedures*

Data was collected as part of a larger and more comprehensive ALS study of 389 patients and 99 caregivers (Felgoise et al., 2007; Chakraborty, Felgoise, Golden, & Simmons, 2005). The ALS clinics involved in this study included the Penn State Hershey Medical Center in Hershey, Pennsylvania, Pennsylvania Hospital in Philadelphia, Pennsylvania, and Drexel/Hahnemann in Philadelphia, Pennsylvania.

*Missing data.* All data was screened for missing responses. If a participant missed up to two items, an attempt was made to contact the participant and ask for a response by telephone, as authorized by the attending neurologist. These participants were assured they could decline to respond, per the instructions in the informed consent document. If responses were not obtained from the blank items, that participant's data was discounted for use in the study. If only one item response was missing, a

conservative approach of estimating was taken and the mean score of the participant's other responses was used. Using a mean score would not confound the data in the direction of positive or negative QOL response and allowed the participant's data to be used for the purposes of this study.

### *Setting and Apparatus*

This study used data previously collected by research assistants at an ALS-designated clinic in central Pennsylvania. The clinic is at a hospital that serves a mixture of rural and suburban individuals living in the region. The population served by this clinic is predominately White. All data is currently housed at PCOM.

Thirty-six multidisciplinary clinics in the country certified by the ALS Association serve significant numbers of individuals with ALS. After diagnosis, patients who attend the clinic and receive a diagnosis of ALS see an occupational therapist, nutritionist, speech pathologist, mental health nurse, social worker, pastoral care coordinator, wheelchair specialist, nurse, and various specialist physicians (e.g., neurologist and pulmonologist). All of the individuals contribute to providing supportive care to the ALS patient and caregiver, as well as to providing care recommendations intended to improve the patient's QOL. However, QOL is complex and multifaceted, and the specific factors and interventions that positively or negatively impact QOL for ALS patients and their caregivers are not well understood.

### *Participants*

Sixty patients and 60 ALS spousal caregivers who attended the ALS-designated clinic in central Pennsylvania for treatment over a 2-year period were considered the primary target of the study. The Institutional Review Boards of the participating institution formerly approved the study, and all participating subjects were required to provide informed consent. This study was part of a larger study with effort to recruit a diverse patient and caregiver sample.

Demographics of recruited patients and caregivers are presented in Tables 1 and 2. ALS patients had a mean age of 60.73, were predominantly White (94.2%), and married (78.4%). The sample contained equal numbers of male and female participants. Caregivers had a mean age of 62.13, were predominantly White (96.3%), obtained postsecondary education (80.8%), and were primarily a spouse or domestic partner (86.0%). The current sample contained predominantly more male caregivers (61.1%) than female caregivers (38.9%).

Table 1.

*Demographic Characteristics of Amyotrophic Lateral Sclerosis Caregivers and Patients*

<i>Variables</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>%</i>
Caregiver Age	62.13	9.93	54	----
Patient Age	60.73	12.10	137	----



Table 2a.

*Frequency Distributions of Amyotrophic Lateral Sclerosis Caregivers*

<i>Variables</i>	<i>N</i>	<i>%</i>
Education		
No/some high school	4	5.8
High school diploma	10	19.2
Some college	8	15.4
Four-year college	13	25.0
Graduate degree	11	21.2
Gender		
Male	33	61.1
Female	21	38.9

## Race

Asian, Pacific Islander	1	1.9
Hispanic, non-White	1	1.9
Caucasian	52	96.3

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## Relationship to ALS patient

Spouse, domestic partner	43	86.0
Parent, child, sibling, other	11	14.0

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## Length of time as primary caregiver

3-11 months	16	32
1-3 years	27	56
4-6 years	4	8

7-10 years	2	4
<hr/>		
Caregiver employment		
Part-time	3	5.7
Full-time	6	11.3
Retired	24	45.3
Disability	17	32.1
Other	3	5.7
<hr/>		
Household Income (thousands)		
Less than 20	3	5.6
20-39	14	25.9
40-59	12	22.2
60-79	12	22.2

80 +	11	20.4
Prefer not to Answer	2	3.7

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Table 2b.

*Frequency Distributions of Amyotrophic Lateral Sclerosis Patients*


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<i>Variables</i>	<i>N</i>	<i>%</i>
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## Education

No/some high school	9	0.8
High school Diploma	40	30.8
Some college	19	14.6
Four-year college	36	27.7
Graduate degree	14	10.8

---

## Gender

Male	68	49.6
Female	68	49.6
<hr/>		
Race		
Asian, Pacific Islander	1	0.7
Hispanic, Non-White	2	1.5
African American	3	2.2
Caucasian	129	94.2
<hr/>		
Living Arrangement		
Alone	19	14.1
With spouse/partner	104	77.0
Long-Term Care Facility	1	0.7

Relative, Friend, Other	2	1.5
<hr/>		
Marital Status		
Currently married	105	78.4
Divorced	14	10.0
Other	12	8.5
<hr/>		

*Patient/caregiver inclusion criteria.* The data of all patients and caregivers attending the ALS-designated clinic in Pennsylvania who met inclusion/exclusion criteria were used in this study. Participants must have received a diagnosis of clinically definite, clinically probable, or clinically probable—laboratory supported ALS, as diagnosed by the attending neurologist, using revised El Escorial Criteria (World Federation of Neurology Research Group on Neuromuscular Diseases, 1994; Brooks et al., 2000, p. 294).

Caregiver requirements included being a spouse or domestic partner functioning as the primary caregiver for an individual with clinically definite, clinically probable, or clinically probable—laboratory supported ALS, as diagnosed by the attending neurologist using revised El Escorial Criteria (Brooks et al., 2000, p. 294).

The present study considered primary caregivers to be spouses or domestic household partners who assumed primary responsibility for a patient's emotional support, activities of daily living, administration of medications, provision of any special nutrition plan, and other aspects of physical care during the course of the disease (Le et al., 2003). Spousal caregivers must have provided primary care for a spouse with ALS for at least 3 years, did not receive pay for the caregiving, provided the majority of caring hours per day, and resided with the patient.

*Patient/caregiver exclusion criteria.* Patient exclusion criteria includes data of those patients who presented with dementia or other cognitive impairment or were under 18 years of age. Caregiver exclusion criteria include those individuals who were unwilling or unable to provide informed consent or who presented with a history or severe psychiatric disorders. Lay caregiver data for patients with ALS and comorbid disturbances such as dementia, medical problems (e.g., cancer), and severe psychiatric disorders (e.g., schizophrenia), as determined by the attending neurologist, were also excluded from the study. Such complexity brings a host of unique caregiving issues that will not be addressed within the design of this study.

### *Criterion Measures*

The study used archival data from the following patient-participant measures: Idler Index of Religiosity, BMMRS, and ALSSQOL—R. The study also used archival data from the following caregiver-participant measures: LOT—R, BMMRS, and Adult State Hope Scale.

*Quality of life.* Patients' QOL was assessed using the ALSSQOL—R. The ALSSQOL—R is a 46-item self-report questionnaire, which is scored on a 0 to 10 Likert scale, with 0 being least desirable and 10 being most desirable. Scoring for the measure requires transposing several items prior to calculating the score. The original 59-item version of the ALSSQOL—R questionnaire was shortened to 46 items to facilitate completion for patients. The factors load into a total of six categories: negative emotion (13 items), interaction with people and the environment (11 items), intimacy (seven items), religiosity (four items), physical symptoms (six items), and bulbar function (five items). Forty-six of the 59 items account for QOL factors. The questionnaire takes 10 to 25 minutes to complete, with an average of 15 minutes for most patients. The measure demonstrates sound psychometric properties. The internal consistency ranges from 0.75 to 0.93. Cronbach's alpha for the ALSSQOL—R ranges from 0.74 to 0.75. It also appears to be a valid instrument as demonstrated by convergent, concurrent, and discriminant validity with other well-established measures (Simmons et al., 2006).

*Religiosity/spirituality.* Patients' religiosity was assessed using the Idler Index of Religiosity. The Idler Index of Religiosity is a four-item index, with two items that assess public religiosity and two items that assess private religiosity. Answers are on a three and



four point likert scale and scores are totaled to produce public, private, and the total religiosity scores (Idler, 1987).

The index of public religiosity consists of two questions concerning congregational social contact; frequency of attendance at religious services and the number of church members known to the respondent. Cronbach's alpha for the two-item scale is .64. The index of private religiosity consists of two items concerning subjective religious experiences; the manner in which the respondent perceives religiosity and the amount of strength and comfort the individual gains from religious practices. Cronbach's alpha for the two-item scale is .72.

Patients' religiosity and spirituality were assessed using the BMMRS, which consists of multiple domains that measure religious and spiritual beliefs, activities, coping, and values. An abbreviated set of questions with regard to various spiritual and religious experiences of ALS will be selected from the data. All items are answered on a Likert scale that ranges from 4 to 6 points. Cronbach's alphas ranged from 0.54 for negative religious coping to 0.91 for daily spiritual experiences (Fetzer, 2003). The measure permits selection of items and remains stable under item extraction.

For patients, the following domains were assessed: forgiveness, daily spiritual experiences, and overall self-rank. The domain of forgiveness consists of three questions that deal with forgiving oneself and others and God's forgiveness of the respondent. The daily spiritual experiences index consists of six questions that deal with possible spiritual experiences and the extent to which the respondent feels peace and strength in religion and a union with God. The domain of overall self-rank consists of three questions that deal with total religiosity and spirituality. The total number of analyzed questions was 13.

### *Predictor Measures*

*Optimism.* Caregiver optimism was measured using The LOT—R, which consists of 10 questions developed to assess individual differences in generalized optimism versus pessimism. According to Scheier et al. (1994), researchers used 6 of the 10 items on the LOT—R to derive an optimism score, with the other four items used as filler items. Of the six scored items, three are keyed in a positive direction and three are keyed in a negative direction. Respondents are asked to indicate the extent of their agreement with each item, using the following response format: 0 = strongly disagree, 1 = disagree, 2 = neutral, 3 = agree, and 4 = strongly agree.

Additional instructions caution respondents to be as accurate and honest as they can throughout and to try not to let their answers to one question influence their answers to other questions. Respondents are explicitly told that there are no right or wrong answers. For scoring, negatively worded items (i.e., items 3, 7, and 9) are reverse coded before scoring, and responses to these items are then summed with the participants' responses to items 1, 4, and 10 to compute an overall optimism score. Thus, scores in principle can range from 0 to 24. Statistically, according to Scheier and colleagues (1994), the LOT—R item–scale correlations ranged from 0.43 to 0.63, suggesting that each item is partially measuring the same underlying construct, but not to such an extent as to be redundant with other items. Cronbach's alpha for the entire six items was .78, which indicates that the LOT—R exhibits an acceptable level of internal consistency. The

LOT—R also appears to demonstrate fairly stable test-retest reliability and stability of scores across time including test-retest correlations ranging from 0.56 to 0.79.

*Hope.* Caregiver hope was measured using the Adult State Hope Scale, a self-report measure, which consists of six items assessing the respondent's thinking at the moment and rating the "here and now" thoughts on an 8-point scale (1 = definitely false to 8 = definitely true). Cronbach's alpha ranged from 0.82 to 0.95, with a median of 0.93. The measure has convergent validity with other scales including the Dispositional Hope Scale, Daily Report Form—Events, and Positive Affect Scale, as well as with overall self-esteem and negative affect. Scoring is achieved by simply totaling the numbers (Snyder et al., 1996).

*Religiosity/spirituality-caregiver.* Caregiver religiosity and spirituality were assessed using the BMMRS. For caregivers, the following domains were assessed: positive religious coping (religiosity), negative religious coping (religiosity), religious intensity (religiosity/spirituality), daily spiritual experiences (spirituality), and beliefs and values (religiosity/spirituality). The positive religious coping index contains three items that measure the respondent's sense of meaning and control, whereas, the negative religious coping index contains two questions that reflect a loss of control and a negative coping style. The religious intensity domain consists of two questions that deal with the extent of the respondent's overall sense of religiosity and spirituality. The daily spiritual experiences index consists of six questions that deal with possible spiritual experiences and the extent to which the respondent feels peace and inner strength and a union with

God. The domain of beliefs and values consists of four questions that deal with life after death. The total number of questions analyzed in this section was 15.

*Religiosity/spirituality-patient.* For patients, religiosity and spirituality were assessed using the BMMRS. The following domains were assessed in this section: forgiveness (religiosity/spirituality), daily spiritual experiences (spirituality), and overall self-rank (religiosity/spirituality). The total number of questions in this section was 13. Patient religiosity was also assessed using the Idler Index of Religiosity. The descriptions are explained elsewhere.

### *Data Analysis*

Statistical analyses were performed on the data from the patient and caregiver measures, using statistical software from SPSS Graduate Pack 11.0 for Windows (SPSS, Inc., 2001).

Demographic characteristics were summarized by calculating means and standard deviations for continuous variables, such as age. Frequencies were calculated for nominal or categorical data such as race or gender. Bivariate correlations were conducted to analyze the relationships between patient negative emotion and both patient religiosity and spirituality as well as between patient religiosity and spirituality and both caregiver hope and optimism. Multiple regression analyses were conducted to explore the relationship among patient negative emotion and caregiver optimism, hope, religiosity, and spirituality.

If a respondent elected not to complete a particular questionnaire or the caregiver and patient were not matched on a questionnaire, the participant was eliminated from the analysis for that measure. Such was the case with the Idler Index of Religiosity. The Idler Index of Religiosity has been found to correlate highly with the ALSSQOL—R on the variable of religiosity (i.e.,  $r=.83$ ; Simmons et al., 2006), which suggests a good and valid measure. Since a larger proportion of the sample who have matched data have completed the ALSSQOL-R, this measure was chosen in place of the Idler Index of Religiosity measure for selected hypotheses.

The study utilized archival data collected from a central ALS clinic and hospital to examine the effect of ALS caregiver religiosity and spirituality, as well as the connection with positive psychological factors, on the QOL in ALS patients. By examining the predictor variables (e.g., caregiver religiosity and spirituality and positive emotions), the current study explored the effect on the criterion variables (e.g., the patient's QOL) measured by negative emotion and search for meaning through spirituality and religiosity. The measures for the patients consisted of the BMMRS, Idler Index of Religiosity, and the ALSSQOL—R. The measures for the caregivers consisted of the BMMRS, LOT—R, and the Adult State Hope Scale. All measures demonstrate good reliability and validity.

## CHAPTER 4

## Results

Few studies have explored the effects of caregiver religiosity and spirituality and positive emotions on quality of life in ALS patients. Chakraborty (2007) may have been one of the first researchers to investigate the concept of resiliency factors in the population of caregivers of ALS patients within the theoretical framework of positive psychology. Chakraborty's study focused on the constructs of hope, optimism, social problem solving, relationship satisfaction, and religiosity/spirituality in caregivers of ALS patients. As stated earlier, much of the caregiver coping research has been from other health-related fields such as Alzheimer's disease, oncology, and HIV/AIDS. Thus, although this study is in many ways similar to the study conducted by Chakraborty, the current study is markedly different. The current study utilized distinct measures aimed at discerning the relationship among positive psychology factors (e.g., hope and optimism), religiosity and spirituality, and the interaction of the patient and caregiver in the coping process as they relate to patient QOL.

### *Sample Representativeness*

Tables 1 and 2 describe the primary characteristics and the demographics of the patient study sample ( $n = 137$ ) and the caregiver sample ( $n = 54$ ). The majority of the patients were White (94.2%), with an average age of 60.73, ranging from 48 to 72 years. Many of the patient sample possessed a high school diploma (30.8%) or a four-year

degree (27.7%), and most patients in the sample reported living with a significant other/partner (77%), being married (78.4%), and either being retired (41.9%) or collecting disability (31.8%).

Sixty-one percent of caregivers were male and 38.9% female and were predominately White (96.3%). Most caregivers had a four-year college degree (25%), graduate degree (21.2%), or high school diploma (19.2%). Respondents were either retired (45.3%) or on disability (32.1%). Most caregivers worked full-time outside of the home before the diagnosis of ALS (38.6%) and started working inside in the home after providing care to the patient (12.8%). Approximately 44.4% of the caregiver sample reported taking psychiatric medication.

### *Descriptive Statistics*

A summary of the means, standard deviations, ranges, and minimum and maximum scores for the instruments in this study is presented in Tables 3 to 5. Patients ( $n = 137$ ) had a mean score of 32.50 ( $SD = 8.08$ ) on the ALS Functional Rating Scale—Revised (ALSFRS—R), a measure of strength, function, and quality of life, with the lowest reported score 8 and the highest 48. Each item is scored on a 10-point scale ranging from 0 to 40 with 0 as the least desirable situation and 10 being the most desirable situation. The reported range and mean found in this study reflect an overall higher functioning subset of patients. Additionally, patients had a mean score of 87.16 ( $SD = 24.19$ ) on ALSSQOL—R Negative Emotion subscale, which consists of 13 items.

A mean of 87.16 indicates that patients in the sample reported the experience of negative emotion, but were, overall, not very depressed.

Table 3.

*Descriptive Statistics: Amyotrophic Lateral Sclerosis Caregiver Scores*

<i>Instrument</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>	<i>Minimum</i>	<i>Maximum</i>
Adult State Hope Scale	36.11	8.92	36	11	47
LOT—R	31.83	6.06	32	10	42
Level of Care Index	6.85	3.22	12	1	13
BMMRS	98.91	27.19	112	39	151

Table 4.

*Descriptive Statistics: Amyotrophic Lateral Sclerosis Patient Scores*

<i>Instrument</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>	<i>Minimum</i>	<i>Maximum</i>
ALSFRS	32.50	8.08	40	8	48
ALSSQOL-R					



Negative emotion	87.16	24.19	118	12	130
Religiosity	25.83	13.10	7	2	9
Idler Index of Religiosity					
Public	6.25	2.39	8	2	10
Private	5.78	1.26	5	2	7
Total score	12.04	3.33	13	4	17
BMMRS					
Forgiveness	4.70	1.78	9	3	12
Daily spiritual experiences	14.49	7.74	30	6	36
Overall self-rank	3.81	2.45	22	2	24
Manual Muscle Test	60.73	12.10	81	6	87

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 Table 5.

*Descriptive Statistics: Amyotrophic Lateral Sclerosis Patient  
and Caregiver Matched Scores*

<i>Instrument</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>	<i>Minimum</i>	<i>Maximum</i>
<b>ALSSQOL—R</b>					
Negative emotion	88.14	24.06	106	24	130
Religiosity	25.83	13.10	40	0	40
<b>Idler Index of Religiosity</b>					
Public	6.04	2.38	7	2	9
Private	5.85	1.26	5	2	7
Total score	11.88	3.36	12	4	16
<b>BMMRS</b>					
Forgiveness	4.73	1.97	--	--	--
Daily Spiritual Experiences	16.31	8.84	--	--	--

Overall Self-Rank	3.96	1.64	--	--	--
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Patients ( $n = 137$ ) had a mean total score of 4.70 ( $SD = 1.78$ ) on the Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) Forgiveness subscale, which is one of 12 scales on the BMMRS. On the BMMRS, the highest possible raw score is 176 and lowest possible score is 36, with lower scores reflecting a tendency to be more religious and spiritual. In this study, instead of incorporating all 12 subscales, the data from three were analyzed. On the forgiveness subscale, the lowest reported score was 3 and highest was 12 (with a possible range of 3 and 12). The score represents the reduction of stress through the resolution of conflict. The mean of 4.70 indicates that the sample was, was on average, more forgiving of themselves, others, and in their relationship with a higher power. Patients had a mean score of 14.49 ( $SD = 7.74$ ) on the BMMRS subscale of daily spiritual experience, with the lowest score 6 and highest 36 (with the possible range of 6 and 36). The total score represents the amount of exposure to psychophysical religiousness/spiritual states by the patient. A mean of 14.49 indicates a moderately spiritual patient sample. Patients had a mean score of 3.81 ( $SD = 2.45$ ) on the BMMRS subscale of overall self-rank, with the lowest score 2 and highest 24. This mean score of 3.81 indicates that, on average, patients viewed themselves as more spiritually opportunistic, hopeful, and peaceful.

Patients ( $n = 137$ ) scored a mean of 6.25 ( $SD = 2.39$ ) on the Idler Index of Religiosity Public subscale with the lowest score 2 and the highest 10. This score indicates a patient sample that, on average, is more concerned with congregational social

contact and frequency of attendance at religious services. Patients had a mean score of 5.78 ( $SD = 1.26$ ) on the Idler Index of Religiosity private subscale with the lowest score 2 and the highest 7. This reflects a patient sample, on average, more likely to derive strength and comfort from inner religious experiences. Patients in this sample scored a mean of 12.04 ( $SD = 3.34$ ) on the Idler Index of Religiosity total score subscale, with the lowest score 4 and the highest 7. This lower mean score reflects higher reported religiosity and spirituality by the patient sample.

The following results are based on a subsample of the above and contain matched caregiver-patient data (see Table 5). Due to the matching process, the sample size decreased drastically ( $n = 26$ ) on the Idler Index of Religiosity, as it was not administered at each data collection site. Therefore, because the Idler Index of Religiosity is highly correlated with the ALSSQOL—R, religiosity subscale, and because it suggests a good measure and a high correlation (i.e.,  $r = 0.83$ ), the ALSSQOL—R was chosen as a valid measure of religiosity and was used in place of the Idler Index of Religiosity since a larger proportion of our sample who have matched data completed the ALSSQOL—R. In addition, it must be noted that this study came from a larger, more comprehensive ALS study of 389 patients and 99 caregivers (Felgoise et al., 2007; Chakraborty, Felgoise, Golden, & Simmons, 2005).

Caregivers ( $n = 54$ ) had a mean score of 36.11 ( $SD = 8.92$ , minimum of 11 to a maximum of 47) on the Adult State Hope Scale (SHS), a six-item dispositional self-report measure of an individual's ongoing goal-directed state hope thinking and orientation (Snyder et al., 1996). According to Snyder and colleagues, the total SHS reflects the theorized agency and pathways components of hope. Summing the three

agency and three pathways items produces the total State Hope score (possible range of 6 and to 48). The mean score of 36.11 indicates that the current caregiver sample reported an increased capacity to initiate and sustain reachable goals.

The Idler Index of Religiosity, which was replaced by the ALSSQOL—R Religiosity subscale for select hypotheses due to the small sample size completing the IIR, provided an average total public religiosity standard score ( $M = 6.04$ ,  $SD = 2.38$ , minimum of 2 and maximum of 9), private religiosity ( $M = 5.85$ ,  $SD = 1.26$ , minimum of 2 and maximum of 7), and overall total score ( $M = 11.88$ ,  $SD = 3.36$ , minimum of 4 and maximum of 16) for matched participants (caregiver and patient). These scores indicate that patients experienced increased public and private spirituality as expressed in a more active prayer life, congregational presence, and spiritual experience.

Patients ( $n = 54$ ) had a total mean score of 25.83 ( $SD = 13.10$ , minimum of 0 and maximum of 40) on the ALSSQOL—R Religiosity subscale and a mean of 88.14 ( $SD = 24.06$ , minimum of 24 and maximum of 130) on the ALSSQOL—R Negative Emotion subscale. A mean of 25.83 indicates moderate religious experiences. A mean of 88.14 indicates a matched patient sample that reports functioning quite well with little depression, yet some experienced some negative emotion. Patients had a mean score of 31.04 ( $SD = 9.60$ ) on the ALSFRS—R, which indicates a decreased rate of negative emotion among the matched sample of patients.

The Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) provided an average total standard score for matched patients ( $n = 26$ ) of 98.92 ( $SD = 27.12$ ), which is obtained by adding the scores of its 12 subscales. However, for this study, the focus will be on three subscales: forgiveness, daily spiritual experiences, and

overall self-rank. Matched patients had a mean of 4.73 on level of forgiveness ( $SD = 1.97$ ), 16.31 on daily spiritual experiences ( $SD = 8.84$ ), and 3.96 on overall self-rank ( $SD = 1.64$ ). On the BMMRS, the highest possible raw score is 176 for all of the 12 subscales combined, and the lowest possible score is 36, with lower scores reflecting a tendency to be more religious and spiritual. These data indicated increased practices and experiences of religiosity and spirituality in the matched patient sample.

The Life Orientation Test—Revised (LOT—R) is a 10-item measure of individual differences in optimism, which provides an overall score that represents the degree to which an individual person expresses optimism. The higher the caregiver score (range 10 to 50), the more optimism the individual experiences. ALS caregivers had an average total score of 31.83 ( $SD = 6.06$ ) on the optimism items, which indicates a highly optimistic sample of caregivers.

### *Inferential Statistics*

Inferential data collected from the Life Orientation Test—Revised (LOT—R), Adult State Hope Scale (SHS), Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS), Idler Index of Religiosity, and the total score on the Amyotrophic Lateral Sclerosis Specific Quality of Life Questionnaire-Revised (ALSSQOL—R), as well as the two ALSSQOL—R subscales on religiosity and negative emotion, were analyzed using correlational methods and regression analyses to determine the predictive value of those variables. The strength of the correlations between the various predictors (hope, optimism, caregiver religiosity and spirituality, and patient

religiosity and spirituality) and patient QOL and religiosity and spirituality (criterion variables) generally determines the accuracy and the strength of the predictions among the variables.

Hierarchical multiple regression is a series of multiple regression analyses in which a new predictor is added, one step at a time, into the equation to predict a given criterion variable. The process identifies the degree of variance unique to the predictor as it is entered into the equation and predicts a scale/normal dependent variable from two or more independent variables. If the variance for the entered predictor is not statistically significant, then the predictor does not contribute uniquely to the variance above what the previously entered predictor has contributed (Allen, 2004). In this investigation, hierarchical multiple regression was used to assess patient negative emotion, as predicted by caregiver hope, optimism, and religiosity and spirituality. The strength of the correlation between the predictors (SHS, LOT—R, and the total score on the BMMRS) and the criterion variable (patient negative emotion) is the determining factor in the results.

### *Correlational Analyses*

Correlational analyses between variables assessed in this study are summarized below.

Table 6.

*Bivariate Pearson Product-Moment Correlations Among Variables*

Variables	Hope (SHS)	Optimism (LOT—R)	Negative Emotion (ALSSQOL—R)
Religiosity (ALSSQOL—R)	.025	.045	.159
Religiosity/spirituality (BMMRS)			
Forgiveness	-.081	-.194	-.250**
Daily spiritual experiences	-.253	-.353	-.295**
Overall Self-Rank	-.205	-.302	-.056
Religiosity (Idler Index of Religiosity)			
Public	---	---	.276**
Private	---	---	.210*



Total score	---	---	.277**
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Note: \* $p < .05$ , two-tailed. \*\* $p < .01$ , two-tailed.

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### *Hope*

Caregiver hope, as measured by the Adult State Hope Scale (SHS) was positively correlated with patient religiosity, measured by the ALSSQOL—R, ( $r = .025$ ,  $p = .858$ , two-tailed) and negatively correlated with spirituality as measured by the total BMMRS subscales of overall self-rank, ( $r = -.205$ ,  $p = .326$ , two-tailed); daily spiritual experiences, ( $r = -.253$ ,  $p = .222$ , two-tailed), and forgiveness, ( $r = -.081$ ,  $p = .701$ , two-tailed). This statistically nonsignificant finding suggests minimal reciprocity between caregivers and patients in terms of the intensity of the caregiving relationship. It appears that caregivers of ALS patients do not have the influential strength, positively or negatively, to affect patients' reciprocal decisions to either engage or disengage religiously or spiritually. Therefore, the data does not support a relationship between caregiver hope and any of the patient subscales of religiosity and spirituality.

### *Optimism*

The predictor construct, optimism as measured by the Life Orientation Test—Revised (LOT—R), was positively correlated with religiosity as measured by the ALSSQOL—R ( $r = .045$ ,  $p = .751$ , two-tailed) and negatively correlated with spirituality,

as measured by the total BMMRS subscales of overall self-rank ( $r = -.302, p = .152$ , two-tailed); daily spiritual experiences ( $r = -.353, p = .091$ , two-tailed), and forgiveness ( $r = -.194, p = .363$ , two-tailed). This statistically nonsignificant finding suggests that caregivers' level of optimism does not influence the patients level of spiritual or religious engagement. The absence of relationship suggests that caregivers' optimistic attitudes may not have a positive or a negative effect on ALS patients. Therefore, the data does not support a relationship between caregiver optimism and any of the patient subscales of religiosity and spirituality.

### *Quality of Life*

The psychological domain of quality of life, specifically negative emotion, measured by the ALSSQOL—R, was positively correlated with the Idler Index of Religiosity public subscale ( $r = .276, p < .01$ ), private subscale ( $r = .210, p < .05$ ), and total score ( $r = .277, p < .01$ ). Negative emotion was inversely correlated with the BMMRS subscales for forgiveness ( $r = -.250, p < .01$ ), daily spiritual experiences ( $r = -.259, p < .01$ ), and overall self-rank ( $r = -.056, p = .516$ , two-tailed). No statistically significant relationship was found between negative emotion and religiosity, as measured by the ALSSQOL—R ( $r = .159, p = .063$ , two-tailed).

As measured by the IIR, the results indicate a direct relationship between a patient's experience of negative emotion and practice of religiosity, whether publicly, such as going to church, or privately, such as prayer, and total feelings of religiosity. Additionally, the findings indicate an inverse relationship between patients' experience of

negative emotion and both forgiveness and daily spiritual experiences. This indicates that patients who are more depressed will feel less forgiveness and rely less often on daily spiritual guidance than patients who are less depressed. There was no relationship between negative emotion and religiosity, as measured by the ALSSQOL—R, which indicates that a patient's experience of negative emotions does not significantly influence the practice of religion. Patients may be coping in other ways. Overall, although these findings are small or nonsignificant, they represent strides in understanding the relationship between a patient's conceptualization of negative emotion and practice of public and private religiosity, spirituality, and inner forgiveness.

### *Regression Analyses*

#### *Regression with Level of Care as Criterion Variable*

Hierarchical multiple regression analyses were conducted to determine if the caregiver factors (i.e., hope, optimism, and religiosity and spirituality) predicted patients' quality of life in the psychological domain of negative emotion above and beyond patient physical functioning, religiosity and spirituality, and level of care provided by the caregiver. The order of entry of the variables into the four regression equations was: religiosity, spirituality, hope, and optimism. The variables of caregiver level of care, patient physical functioning, and patient religiosity and spirituality were entered and remained constant.

As seen in Tables 7 through 10, the results revealed that the caregiver variables predicted 25.4% of the variance in negative emotion, as rated by the ALSSQOL—R,  $F(1, 54) = 7.82, p = .011$ . These results indicate that caregivers' level of hope, optimism, and engagement in religious and spiritual experiences do not significantly influence patients' experience of negative emotion. Although this was not predicted, it is not a negative finding. It simply indicates that the patient-caregiver relationship in ALS may be different from, and perhaps less dependent, than those relationships suggested in the literature for other chronic illnesses. This relationship could actually prove beneficial to both individuals being less interdependent.

Table 7.

*Summary of Hierarchical Regression Analysis for Variables Predicting Patients' Negative Emotion and Quality of Life*

Model	<i>R</i>	<i>R</i> <sup>2</sup>	Adjusted <i>R</i> <sup>2</sup>	SE of the Estimate
Level of Care Index	.540	.292	.254	20.31

Table 8.

*Analysis of Variance*

<i>Level of Care Index</i>	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
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Regression	1	3227.51	3227.51	7.82	.011
Residual	19	7837.73	412.51		
Total	20	11065.24			

Table 9.

*Beta Coefficient*

<i>Variable</i>	<i>Coefficient</i>	<i>SE</i>	<i>Standard Coefficient</i>	<i>t</i>	<i>p</i>
Level of Care Index	-3.68	1.32	-.540	-2.80	.011

Table 10.

*Excluded Variables*

	<i><math>\beta</math></i>	<i>t</i>	<i>p</i>	<i>Partial Correlation</i>	<i>Collinearity Statistics</i>
Manual Muscle Test	.230	1.13	.273	.258	.891
ALSSQOL—R	.161	0.73	.473	.170	.789

## BMMRS

Overall self-rank	-.132	-.656	.520	-.153	.944
SHS	.102	.500	.623	.117	.928
LOT—R	.065	-.255	.802	-.060	.599

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*Hypotheses: Relevant Findings**Hypothesis 1*

Hypothesis 1 was tested using Pearson product-moment correlation. Hypothesis 1 predicted a significant inverse relationship between patient negative emotion and patient religiosity and spirituality. As shown in Table 6, although significant for some variables, this hypothesis was unsupported.

There were significant positive relationships between a patient's experience of negative emotion and a patient's engagement in public religiosity ( $r = .276, p < .01$ ) and private religiosity ( $r = .210, p < .05$ ), and overall engagement in religious practices ( $r = .277, p < .01$ ) according to the IIR. Therefore, according to this measure, there was a small relationship between engaging in religious practices and experiencing higher levels of negative emotion. The findings also indicate an inverse relationship between a

patient's negative emotion and both forgiveness ( $r = -.250, p < .01$ ) and engagement daily spiritual activities that may provide peace and strength and a union with God ( $r = -.259, p < .01$ ), according to the BMMRS. The data reflects the following: (a) as patients become more depressed, they are less forgiving of themselves, others, and their relationship with God, and (b) as patients become more depressed, they are less likely to seek spiritual strength from God as a method of coping with terminal illness. According to the ALSSQOL—R, there was no relationship between negative emotion and religiosity ( $r = .159, p = .063$ , two-tailed).

### *Hypothesis 2*

Hypothesis 2 was tested through Pearson product-moment correlation. Hypothesis 2 predicted a direct relationship between caregiver hope and both patient religiosity and spirituality. The results indicated that caregiver hope was not significantly correlated with patient religiosity ( $r = .025, p = .858$ , two-tailed) and spirituality ( $r = -.205, p = .326$ , two-tailed). Therefore, hypothesis 2 was unsupported.

### *Hypothesis 3*

Hypothesis 3 was tested through Pearson product-moment correlation. Hypothesis 3 predicted a direct relationship between caregiver optimism and both patient religiosity and spirituality. The results indicated that caregiver optimism was not significantly

correlated with patient religiosity ( $r = .045$ ,  $p = .751$ , two-tailed) and spirituality ( $r = -.302$ ,  $p = .152$ , two-tailed). Therefore, hypothesis 3 was unsupported.

#### *Hypothesis 4*

Hypothesis 4 was analyzed using a regression analysis. The hypothesis suggested that patient negative emotion would be predicted by caregiver hope, optimism, and engagement in religiosity and spirituality, above and beyond the following variables: caregiver level of care, patient religiosity and spirituality, and patient physical functioning. The results revealed that caregiver variables were not the best predictors of patient negative emotion. Therefore, hypothesis 4 was unsupported.



## CHAPTER 5

### Discussion

#### *Significant Findings*

The present study examined the effects of caregiver religiosity and spirituality, caregiver positive emotions, and the interdependent nature of the patient-caregiver relationship on the patient's psychological well-being and social satisfaction. Overall, the findings of the study do not suggest that caregiver variables are responsible for the observed variance in the QOL of their ALS patient spouses. The findings of the study also suggest that participants did not highly utilize religious or spiritual methods as viable coping strategies under the stress of a terminal illness, as predicted. The only significant relationships, albeit small, were between patients' negative emotion and patients' forgiveness, daily spiritual experiences, subjective view of overall rank of religiosity, and their engagement in public and private religious activities.

#### *Caregiver Variables*

Positive emotion, including optimism and hope, and religiosity and spirituality, had less overall significant predictive ability than expected with respect to patients' QOL, as measured by the psychological domain factor of negative emotion. Prior research has generally supported the notion that a significant relationship exists between caregiving

stress/coping and outcomes in patients. For example, Redinbaugh et al. (2003) found that greater caregiver strain was directly related to greater patient needs in ADL, psychological distress, and poorer patient existential QOL. Redinbaugh and colleagues also found that reframing the event, defining the illness in a manageable way, and engaging in improved problem-solving strategies led to lessened caregiver strain.

The absence of impact of the caregiver variables on the patient demonstrates independence rather than interdependence among the sample of ALS caregivers and patients in the present study. This finding is generally contradictory to previous research that demonstrates the belief that hopefulness or hopelessness of the patient or family member affects the other partner in the relationship in an interdependent manner through styles of coping (Borneman et al., 2002; Herth, 1993). It is likely that the participant sample in the present study exhibited less overall negative emotion and was therefore less affected by caregiver negative or positive emotions.

### *Quality of Life*

Another contradictory finding in the present study was in reference to the relationship between patient negative emotion and religiosity and spirituality. According to results, patients did not rely heavily on religious or spiritual coping strategies to aid with negative emotions. Prior research indicates that medical patients and individuals who generally utilized religious and spiritual methods as forms of coping tended to have positive emotions, thoughts, and experiences. For example, Stanton and colleagues (2002) found the presence of hope among other various coping strategies (e.g.,

reinterpreting positively, turning to religion, coping in a problem-focused manner, seeking social support, and accepting the disease) among oncology patients. They suggested that religious coping was more useful for patients possessing lower hope because it provided them with an increased sense of control, meaning, intimacy, and belongingness (Stanton et al., 2002).

Although not predicted at the outset of the present study, there were significant relationships found between negative emotion and both forgiveness and daily spiritual experiences. It appears that patients with increased negative emotion experienced a lessened ability to forgive themselves and others and experience forgiveness by God, as well as a decreased need to engage in daily spiritual experiences. It can also be interpreted as the individual who experiences positive emotions also experiences increased forgiveness and engagement in spiritual exercises. This finding is generally supported in the literature, as coping in a problem-focused manner (e.g., seeking information, finding resources, praying and asking a higher power for help/strength, and garnering support from others) increases positive emotions through the use of active coping strategies (Stanton et al., 2002).

The results also suggested a direct significant relationship between negative emotion and total religiosity and public and private religiosity. This finding reveals two things: First, patients in the sample with increased negative emotion tended to engage in more organized and ritualistic experiences to enhance their union with a higher power. This is supported through the results of the correlational analyses. It may be that terminally ill patients take comfort in what is predictable, structured, and controllable, which religion tends to provide for individuals on a larger basis than the flexibility and

unstructured ways of spiritual engagement. Second, the results also indicated that patients experiencing increased negative emotion tended to more often engage in public religiosity. This suggests that the present patient sample may have been looking for social connection as well as support and union with a higher power, and perhaps structure, predictability, and meaning. This finding is contradictory to the prediction that when patients did not attend religious services as coping, they would experience depression, and it was expected that depressed patients who attended services would experience enhanced mood. The results found quite the opposite, which may also demonstrate ambivalence on the part of patients in their relationship with God or a determination to seek out guidance and answers to end-of-life questions in the midst of their terminal illness.

### *Hypotheses*

Hypothesis 1 stated that there would be an inverse relationship between patient negative emotion and both patient religiosity and patient spirituality. That is, medical patients who generally utilized religious and spiritual methods as forms of coping would tend to have positive emotions, thoughts, and experiences (i.e., decreased negative emotion). The findings do not support this hypothesis. In summary, the relationship between the psychological domain of quality of life, which is measured as negative emotion in this study, was positively correlated with public religiosity, private religiosity, and patients' total religious scores. Additionally, a statistically nonsignificant relationship was found between negative emotion and religiosity.

One explanation for these unexpected findings is that this sample of medical patients were higher functioning, educated, and appeared to be supported by others, and therefore exhibited lower levels of negative emotion. This impacted their overall perception of the illness and their need for various coping skills. It is also possible that patients coped with ALS using mechanisms other than religious experiences. According to the results, patients slightly preferred public religiosity over private, which indicates the presence of a social connection may be more beneficial in the coping process to patients with ALS. Although this finding is not consistent with previous research that suggests the most significant predictor of decreased depression was reliance on faith or religion as coping rather than social connection (Koenig et al., 1995), other literature supports this finding in that coping through a social network enhances mood and extends life (Daaleman & Kaufman, 2006; Myers, 2000).

Hypothesis 1 also stated that negative emotion would be inversely correlated with forgiveness, daily spiritual experiences, and overall self-rank. The findings partially support this portion of the hypothesis. To further explain, although the correlation is small, there is a relationship between experience of negative emotion and patients' forgiveness for themselves and others and forgiveness from God, as well experience of negative emotion and engagement in spiritual experiences. An alternative explanation for this finding is supported in literature. According to Berman and Davis-Berman (2005), positive or negative thoughts will affect physical health, emotions and mood, and overt behavior. Another explanation for the finding would be that this sample of depressed patients continue in their depressive thought pattern rather than reach out to a higher power or utilize spiritual thoughts or feelings as productive coping mechanisms to help

with the ALS diagnosis or illness progression. This sample of patients were fairly educated, supported by caregivers, and higher functioning; perhaps they coped with ALS in another manner.

Hypothesis 2 stated that there would be a direct relationship between caregiver hope and both patient religiosity and patient spirituality. The findings do not support hypothesis 2. In summary, caregiver hope was not significantly correlated with patient religiosity and spirituality. One explanation for this finding is that caregivers in the present sample were high functioning, independent, and educated individuals who coped adaptively with the stressors of caretaking. Another explanation is that perhaps, regardless of the experience of hope or religiosity/spirituality, this sample of caregivers coped other ways, perhaps through supportive friends, family resources, or hobbies. Additionally, the majority of caregivers were males, who are typically less externally emotional, which may have influenced the coping style and interdependent relationship with the patient.

The findings suggest that caregiver coping does not affect patient coping, which in this case indicates that the present sample was highly independent. The patients and caregivers in this study did not demonstrate a reciprocal relationship, which is contradictory to the literature (Borneman et al., 2002). Although reciprocity in spousal patient-caregiver relationships has not been examined adequately in the literature, especially among ALS dyads, it has been demonstrated among intimate relationships of nonmedical individuals (Anderson, 2001). However, according to Allen (2004) many studies fail to use the same measures to assess the same variables across participants, which is the case here. Perhaps the present sample had access to external resources that

educated them on the literature explaining caregiver burden and the reciprocal harm it causes to patients. Other explanations for this nonsignificant finding may be simply the nature of the measurability of the intrinsic construct of hope, the difficulty researchers have had over the years with defining religiosity and spirituality, and the limited sample size. Therefore, given the small sample size, these results should be interpreted conservatively and considered exploratory.

Hypothesis 3 stated that there would be a direct relationship between caregiver optimism and both patient religiosity and patient spirituality. The findings do not support hypothesis 3. The results indicated that caregiver optimism was not significantly correlated with patient religiosity and spirituality. Therefore, hypothesis 3 was unsupported. One explanation for this finding is variations in caregiver demographics, which could affect the independence in the caregiver-patient relationship, degree and type of external coping, and utilization of external resources. Although the majority of caregivers and patients were in spousal relationships, their relationship satisfaction was not as part of this study. Perhaps they were disconnected from each other and utilized separate coping methods. Another explanation for the nonsignificant finding may be the sample size and the nature of the measurability of the constructs. Finally, the finding was unexpected as it contradicts most fairly recent caregiver-patient literature that posits a positive coping relationship reflective of optimism is likely to provide a sense of meaning, purpose, and direction for the patient (Chang et al., 1998; Gottlieb & Rooney, 2004).

Hypothesis 4 held that patient negative emotion would be predicted by caregiver hope, optimism, and engagement in religiosity and spirituality, above and beyond the

following variables: caregiver level of care, patient religiosity and spirituality, and patient physical functioning. The results revealed that caregiver variables predicted 25.4% of the variance in negative emotion. Therefore, hypothesis 4 was unsupported. One explanation for this finding is the use of different predictor variables for one spouse and the criterion variable for the other spouse (Allen, 2004). According to Allen (2004), this represents a limitation as the constructs being measured lack consistency across participants. However, support for this hypothesis may more reliably have been found if predictor and criterion variables were collected from the patients and caregivers separately, rather than with regard to the relationship between them.

Another explanation for the finding is the small sample, which resulted in a lack of power for statistical analysis. As stated previously, this study is part of a larger and more comprehensive ALS study. Therefore, given the sample size, interpret the results conservatively and consider the study exploratory.

Finally, the absence of an interdependent relationship between spouses and caregivers, although predicted and generally supported in the literature, is relatively positive because it would not be beneficial for patients' quality of life to be influenced by their caregivers' negative emotional state. In this case, according to the results, if patients are not influenced by caregivers' positive states and emotions, they are not influenced by caregivers' negative states and emotions, which could be detrimental to the disease process and QOL. In addition, it was assumed that patients' psychological well-being would be dependent upon caregivers emotional states, coping, and functioning; however, the results indicate that QOL is more broadly defined for patients and not largely dependent on caregivers. This is not to say that caregiver emotional states and



experiences do not influence patient QOL, but QOL may be a more complex construct than initially thought. It might be beneficial to conduct additional research to more accurately understand the factors that contribute to ALS patient QOL and psychological well-being and to more precisely measure the construct. This corroborates the work of Allen (2004), who found similar results among spousal patient-caregivers indicating that patient QOL was more independently determined with regard to emotional well-being rather than psychological well-being.

### *Limitations of the Study*

This study has several notable limitations within its design, measurement, and recruitment strategy. For instance, the recruitment strategy compromised external validity because it involved solicitation by each clinic director of a convenience sample of caregivers and patients known to the director and staff. Those caregivers and patients who agreed to participate may have reported higher positive affect scores than they actually felt because they wanted to be perceived as model caregivers to the clinic staff. The social desirability of their responses may have positively skewed the results of the study.

Another potential threat to external validity is possible sampling bias. The study participants recruited from within the clinic setting may differ from those who are not part of an ALS network because of the extensive attention, social support, and resources provided by the medical doctors and staff. Caregivers in the ALS network have increased support and may perceive their situation as more hopeful and optimistic, engage in more

religious and spiritual experiences, and report less psychological distress than non-clinic-attending caregivers, whom the study does not include. For the most part, the ALSFRS-R rating was fairly high. Perhaps the caregiver would have been more psychologically distressed had the patient been functioning at a lower physical level. Similarly, with increased support by medical doctors and staff, and with increased access to higher technology resources, their QOL may have been markedly improved over that of individuals who do not have access to those resources. Therefore, caution should be taken when generalizing from this caregiver and patient sample to one without as many resources, or as much social support and attention.

This study's ethnic and racial sample composition is another potential limitation. The clinic made an effort to recruit a representative sample of the ALS population of the region, however, it is likely that the generalizability of the findings with respect to caregiver constructs (96.3%) and patient constructs (94.2%) may be limited by an overrepresentation of White participants. In addition, ALS usually has a high prevalence in males, which would lead to a higher predominance of female caregivers; however, this series of caregivers were predominately male (61.1%).

The correlational design of the study does not allow conclusions to be made about causation. The goal of the study was not to establish the cause(s) of negative emotion or religiosity and spirituality, but to instead develop a better understanding of the factors that may positively or negatively influence patient variables.

Another potential limitation involves the instruments of measurement. All of the measures included in the study employ a self-report format. It is well known that self-

report instruments lack the ability to capture all aspects of a construct and tend to lack validity and sometimes accuracy.

It is also possible that caregivers and patients may have come to the clinic the day of the study after having a particularly stressful week, morning, or specific life event and may have temporarily interjected subjective distress onto one or more of the measures. Therefore, the caregivers' and patients' responses on that day may not be an accurate representation of an overall psychological state and QOL. The results should be interpreted in light of this suggestion.

A longitudinal investigation may better capture the impact of the caregiver and patient constructs as they develop and impact each other. Findings from such a study would allow for a better understanding of the patients' response to the illness, how those response impact the caregiver, how the caregiver impacts the patient, what role coping plays in the lives of the members of the dyad, both separately and together, and the manner in which professionals should best intervene with the patient and caregiver. A cross-sectional study, as completed here, is difficult to generalize across samples for many reasons, amidst the fact that the day the participant completes the measures may not be reflective of their true psychological state in the overall scheme of the terminal illness.

The sample size was not large enough to achieve sufficient power. It is believed that the significance of the results would increase to the .05 level with the increase of the sample size ( $n = 58$ ). Therefore, the limitation in power should be considered when interpreting the results of this study.

A threat to construct validity relates to the definitions of *religiosity* and *spirituality* and of *QOL* in this investigation. Researchers have historically struggled with defining religious and spiritual experiences (Cohen & Koenig, 2003; George, Larson, Koenig, & McCullough, 2000). In addition, although clarification has been attempted in this study, there have been several definitions of QOL in the literature. Finally, interpretations of the findings, including the presence or absence of identified predictive relationships, may not be completely accurate due to the phenomenological nature of the variables under study.

The study was limited to archival data, which limited the ability to select appropriate variables and measures.

### *Clinical Implications*

It was anticipated that caregiver variables would directly influence patient variables. It is plausible that the other variables (e.g., spousal caregiver coping through spirituality and religiosity, caregiver optimism and hope, and similar religious affiliation), achieved by spending time together and experiencing a cognitive connection would increase a patient's self-perception of QOL by making the individual more positive and psychologically and socially healthy. However, the reverse may also be true: a patient's psychological state and openness to engaging in religious or spiritual activities may influence the hope and optimism of the caregiver through the deep connection felt within the relationship. Furthermore, it may also be the case, if the caregiver is not properly taking care of him/herself, that the impact of burden will have psychological

ramifications on the ALS patient. The possibility exists that a subset of patients and caregivers, regardless of the amount of meaningful time spent together, do not experience such a cognitive connection in that one's psychological or emotional state does not affect the other. In that case, the disconnection may filter into the social realm without the impact of spirituality.

This study may be one of the first to examine the interaction between the caregiver and patient in the context of caregiver coping variables and QOL in ALS. A positive caregiving environment appears to be critical to producing increased QOL in patients of other terminal illnesses (Redinbaugh et al., 2003; Schulz et al., 1995). A positive environment may include positive coping strategies (e.g., use of religiosity/spirituality, as well as hope and optimism) or caregiver expression of positive emotions (e.g., optimism, hope) that may be easily transferred onto the patient through the caregiver-patient cognitive connection. The caregiving role is taxing, yet extremely important. Although it was predicted that the reciprocal relationship between the patient and caregiver would impact the patient's perception, course, and experience of the disease, results of this study indicate no such existence of reciprocity between the caregiver and the patient.

The finding is startling yet not discouraging, as it demonstrates the role of independence in the caregiving relationship that often goes unreported in the literature. If increased optimism and hope were not found to bolster patients' religiosity and spirituality, then decreased optimism and hope will not harm the patient's experience of religiosity or spirituality and psychological well-being (i.e., negative emotion). Additionally, although the sample was higher functioning and did not exhibit extensive

expressions of negative emotion, religiosity and spirituality did not appear to be significant coping strategies for patients and caregivers. It is unclear in this study what other methods of coping were used to counter the effects of stress for the ALS patients and caregivers. Perhaps future studies could address ALS caregiver and patient coping skills in a broader fashion. However, future studies may want to investigate the exact mediator variable in the relationship between hope and religiosity/spirituality as forms of coping.

The present study did not find that caregiver variables significantly impacted patient QOL. It appears that a more independent relationship existed in the current sample than was predicted based on previous research studies. This unexpected finding comprises a range of clinical implications for both patients and caregivers struggling with the distress of terminal illness. It is possible, within this contextual finding, that the caregiver will not feel the demands of placing stressors on the patient as well as of the patient projecting negative feelings onto the caregiver. According to Rabkin et al. (2000), caregivers and patients express great concern over each other's feelings and burdens. Additionally, although a reciprocal relationship does not exist in this sample, as predicted, caregiving burden continues to be a significant predictor of psychological distress for caregivers (Adelman et al., 2004; Mitsumoto, 2002; Rabkin et al., 2000; Taylor, 2006; Theis, Biordi, Coeling, Nalepka, & Miller, 2003), and distressed caregivers tend to experience increased rates of depression, financial burden, hopelessness, fatigue, and anxiety (Rabkin et al., 2000).

Essentially, the psychological, physical, and financial strains of caregiving are considerable. According to Cobb et al. (2001), caregivers tend to cope cyclically with

thoughts and feelings, which explains some of the variance seen among the sample.

Perhaps caregivers coped better depending on where they were in their coping with the disease process. Regardless of the independence demonstrated in the relationship in the current study, caregivers face daily battles with grief in an attempt to move forward and deal with the ramifications of the chronic illness.

Despite the physical, psychological, and functional constraints imposed on ALS caregivers and patients, it is possible to lead a quality life. Theoretically, a more positive environment would facilitate increased coping with the illness; therefore, positive coping strategies should be in place as early as possible for both patients and caregivers.

Furthermore, research supports the establishment of meaning in helping caregivers cope with the disease process. Many other coping mechanisms can be put into place to help caregivers and patients achieve increased psychological health, including facilitating social support, increasing communication among the dyad, reframing the illness into an “event” rather than an “illness,” acknowledging why the illness occurred, connecting with church groups, bringing religiosity and spirituality into treatment, and improving the dyad relationship.

It appears that the sample of patients in the present study did not utilize religious or spiritual methods to cope with ALS. It is unclear at this time what method participants used in place of gaining control and predictability through the use of a higher power, or God, or an organized religion. Some terminally ill patients become angry with God at the outset of their illness and blame Him for their illness. Instead of using “a union with God” as a form of coping, these individuals question their existing faith or find other means of dealing with their thoughts and feelings.

### *Conclusions and Future Directions*

Research indicates that most caregivers, at some point, will experience some degree of distress or grief in reaction to the news that a loved one has been diagnosed with a life-threatening illness such as ALS. Caregivers usually take on the role of without time to react to the situation. In the midst of the illness, which comprises a cyclical pattern of grieving each caregiving loss as it occurs, caregivers often forget about attempting to cope with their own thoughts or feelings. In theory, the caregiving role is a selfless act that actually takes a toll on individuals and often leads to feelings of isolation, loss of traditional roles (e.g., work, family, spouse, friend, lover, parent), financial worry, embarrassment, and a loss of leisure time (McDonald, 2001). When individuals do not cope adequately with the burden, other deteriorating symptoms may surface. For example, caregivers may also experience depression, anxiety, and various physical disturbances throughout the course of the disease that pose adjustment difficulties for both the patient and family members (Jacobs & Mitsumoto, 2001). Given the intensity of the caregiving relationship, it would only be natural for some reciprocal influence to occur between the two individuals. For instance, as ALS progresses, patients sense the caregiving stress and tend to worry that they are burdening their family members (Ganzini et al., 2002).

Although the present study did not find a relationship between caregiver variables and patient variables, the interdependence of the caregiver-patient relationship has been well established in research on other chronic illnesses; therefore, the issue remains salient in the area of ALS. Given the previous research supporting the importance of caregiver



variables, such as religiosity, spirituality, and positive emotions as forms of coping in the relationship with the patient, future studies should continue investigating the patient-caregiver relationship and the exact mediator variable in the relationship between hope/optimism and religiosity and spirituality as forms of coping. If future studies can identify and expound upon the patient-caregiver variables that contribute to ALS patient QOL, then treatment alternatives can be explored more readily for patients, caregivers, and the dyad together.

The present study did not find a relationship between patient negative emotion and the use of religious and spiritual coping. Nonetheless, religious and spiritual experiences have well-defined benefits in the literature, including increased strength, locus of control, psychological advantages (increased optimism and hopefulness), social advantages (through religious communities, church affiliation, and worshipping together), and spiritual advantages (prayer; Curlin, 2004). The current sample did not utilize religious or spiritual experiences to cope with negative emotions. Future researchers may wish to investigate other mechanisms that patients and caregivers use in place of religiosity and spirituality to cope with ALS. Despite these results, we believe that caregiver well-being impacts patient QOL. We are now surveying our caregivers with regard to stress and coping in an attempt to determine how to support the caregivers using an evidence-based approach. This may be a useful topic for a future dissertation.

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